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<b>13. ABSTRACT (Maximum 200 Words)</b> Accumulating evidence indicates that the "biobehavioral model" of health and disease may have considerable relevance for cancer generally, and breast cancer in particular. Broadly stated, this model proposes that what people think and feel affects the state of their health in two basic ways: by affecting their behavioral choices (e.g., smoking) and by affecting biological processes (e.g., cortisol levels) that affect risk and response to disease. Given the complexity of the interactions postulated by the biobehavioral model, to fully explore its implications for breast cancer it will be important to increase the number of researchers with the broad-based training that allows them to conduct truly interdisciplinary research addressing issues that transcend traditional disciplinary boundaries. Our Post-doctoral Training Program in Biobehavioral Breast Cancer Research was designed to provide trainees with advanced degrees in relevant areas (e.g., epidemiology, medicine, psychology, public health) with the necessary intellectual background needed to "speak the language" of the multiple relevant disciplines and with the "hands-on" experience under the tutelage of experienced mentors necessary to do interdisciplinary research and become independent investigators. Trainees have demonstrated proficiency in doing research and reporting results.				
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## **5. INTRODUCTION:**

Despite encouraging news that cancer incidence and mortality rates inched downward in the last decade of the 20th century, breast cancer continues to be a pre-eminent cause of morbidity and mortality among American women. Growing evidence indicates that the "Biobehavioral model" of health and disease may have considerable relevance for cancer generally, and breast cancer in particular. Broadly stated, the Biobehavioral model proposes that what people think and feel affects the state of their health in two fundamental ways: by affecting their behavioral choices (e.g., consumption of alcoholic beverages) and /or by affecting biological processes (e.g., immune defenses) that may affect risk of disease and prognosis. Biobehavioral interactions have received increasing attention in breast cancer research over recent years. Through their effects on behavioral choices, cognitive and emotional factors are now recognized to influence women's risk of developing breast cancer, compliance with screening guidelines, interest and uptake in genetic testing, response to treatment, as well as contribute to quality of life among breast cancer survivors. Although there is some evidence that psychosocial interventions may affect survival, the impact of cognitive and emotional effects on biological processes involved in breast cancer incidence, progression, or recurrence has yet to be elucidated. Effects of cognitive and emotional factors on treatment related side effects are increasingly well documented, however. Perhaps reflecting the dearth of investigators with broad-based interdisciplinary training in this area, few studies have explored the possibility that interactions among psychological factors, behavioral choices, and biology may have important implications for breast cancer (e.g., the risk of developing breast cancer may be particularly high among women who have high levels of stress in conjunction with exposure to environmental toxins).

The importance of promoting broad-based research efforts on biopsychosocial and behavioral factors in all aspects of cancer (prevention, detection, diagnosis, treatment, and long term survival) has recently been emphasized in reports prepared by two blue ribbon panels for the National Cancer Institute. These reports have underscored the need for an expanded emphasis on research examining basic behavioral, psychological and social processes, aimed at increasing our understanding of the mechanisms underlying behavioral change (e.g., alcohol consumption) from the individual level (e.g., perceptions of risk) to the group (e.g., family influences) and society (e.g., social class) levels. In addition, the need for new initiatives in biopsychosocial research to explore interactions among biological, psychological, and social processes in cancer etiology, progression and response to treatment, was also emphasized. These reports have further noted the critical need to develop a cadre of highly trained research scientists with the necessary interdisciplinary skills to effectively and efficiently address these complex issues.

Our Postdoctoral Training Program in Biobehavioral Breast Cancer Research was designed to provide trainees with advanced degrees in relevant areas (e.g., epidemiology, medicine, psychology, public health) with the necessary intellectual background needed to "speak the languages" of the multiple relevant disciplines and with the "hands-on" experience under the tutelage of experienced mentors necessary to do interdisciplinary research and become independent investigators in this underdeveloped area of research.



## **6. BODY:**

During the past year of this four year funded program of postdoctoral training, our primary focus has been the implementation and continued improvement of all aspects of the training program, Task 3 (a-k):

a) Consistent with our proposed developmental plan, we have continued to conduct a nation-wide search for applicants for the postdoctoral positions offered. We have continued to receive large numbers of applications from strong candidates around the country, as well as from abroad.

b) After extensive evaluation, including in person interviews with the strongest applicants, we have recruited excellent trainees.

c) We have conducted a series of Core Course lectures presented by members of the faculty of the Mount Sinai School of Medicine, supplemented by outside speakers with particular expertise on relevant topics. Examples of internal speakers include Dr. George Raptis of the Department of Medicine, who provided an integrated series of three lectures entitled: An introduction to the pathobiology of breast cancer; The clinical management of early stage breast cancer; and, The treatment of metastatic breast cancer. A recent outside speaker was Dr. Gary Winkel of the Graduate Center City University of New York, who gave a mini course introducing advanced statistical analysis with SAS.

d) In addition we have supported a series of research seminars by Mount Sinai faculty and outside speakers to provide Trainees with exposure to recent developments in Biobehavioral Medicine, as well as related disciplines. For example, recent outside speakers have included Dr. Joseph P. Green of the Ohio State University who presented his recent work on "The Efficacy of Hypnosis-Based Treatments for Smoking Cessation," and Dr. Annette Stanton of the University of Kansas, who presented a seminar entitled: "Expressing Emotions and Finding Benefits: Adaptive Strategies for Breast Cancer Patients."

e) As indicated above, both the Core Course Curriculum and Seminar Series have been running over the past year.

f) We continue our emphasis hands-on portion of the training program through the active mentoring of trainees by federally-funded faculty members.

g) The Luncheon Lecture series (sometimes rescheduled as the "Bagel Breakfast" meeting), covering recent journal articles, work in progress by local investigators, and career development considerations by outside speakers has been scheduled and run.

h) Guidance in the development of independent research projects has been provided by the mentors for each Trainee, as well as by feedback from other members of the faculty made more informally as part of the Luncheon Lecture series.

i) Oversight for each Trainee's independent project is being provided by their Mentor and more informally by the rest of the faculty at Work-in-Progress (WIP) presentations as part of the Luncheon Lecture series.

j) Formal evaluations of Trainees and the Program have been conducted (e.g., at the end of each Trainee's first year of the Program).

k) In the first year of each Trainee's participation in the program, the focus has been on preparation of research reports from previous relevant research they may have conducted before joining the program, the preparation of research reports from the data collected from projects previously collected by their Mentors, and the preparation of initial reports concerning data which they collected during their first year of the Program. The development of Trainee's skills in grant writing has been fostered by a formal mini-series of lectures on grant writing; by one-on-one tutorials about the process as their Mentors have written and submitted grants; and by participation in our in-house grant review meetings in which faculty present their preliminary drafts of applications.

## **7. KEY RESEARCH ACCOMPLISHMENTS:**

### **1) Key research accomplishments**

**Conducted training program for 4 Postdoctoral Trainees**

**Recruited trainee applications**

**Evaluated potential trainees**

**Developed and scheduled Core Curriculum**

**Scheduled Seminar Series**

**Ran Core Curriculum and Seminar Series**

**Established "hands-on" research experience for each Trainee**

**Scheduled and ran Luncheon Lecture series**

**Guided development of independent research projects for each Trainee**

**Provided oversight for each Trainee's independent project**

**Conducted formal evaluations of Trainee and Program**

**Facilitated preparation of research reports and grant applications**

## **8. REPORTABLE OUTCOMES:**

**These are grouped alphabetically by Trainee.**

### **DR. JULIE BRITTON (former trainee) – PAPERS:**

**Britton, J.A., Gammon, M. D., Schoenberg, J.B., Stanford, J.L., Coates, R.J., Swanson, C.A., Potischman, N., Malone, K., Brogan, D.J., Daling, J., Brinton, L.A. Risk of breast cancer classified by joint estrogen receptor and progesterone receptor status among women 20 to 44 years of age. American Journal Epidemiology 2002;156(6):507-516.**

**Britton, J.A., Kushi, L., Morabi, A., Bernstein, J., Shore, R., Geringer, W., Rohan, T. The development of a questionnaire to assess past year physical activity in a multi-ethnic/racial urban population. Soz Praventivmed. 2002;47(3):178-94.**

**Gammon, M.D., Neugut, A.I., Santella, R.M., Teitelbaum, S.L., Britton, J.A., Terry, M.B., Eng, S.M., Wolff, M.S., Stellman, S.D., Kabat, G.C., Levin, B., Bradlow, H.L., Hatch, M., Beyea, J., Camann, D., Trent, M., Senie, R.T., Garbowski, G.C., Maffeo, C., Montalvan, P., Berkowitz, G.S., Kemeny, M., Citron, M., Schnabel, F., Schuss, A., Hajdu, S., Vinciguerra, V., Collman, G.W., Orams, G.I. The Long Island Breast Cancer Study Project: Description of a multi-institutional collaboration to identify environmental risk factors for breast cancer. Breast Cancer Research Treatment. 2002;74(3):235-54.**

**Gammon, M.D., Wolff, M.S., Neugut, A.I., Eng, S.M., Teitelbaum, S.L., Britton, J.A., Terry, M.B., Levin, B., Stellman, S.D., Kabat, G.C., Hatch, M., Senie, R., Berkowitz, G.S., Bradlow, H.L., Garbowski, G., Maffeo, C., Montalvan, P., Kemeny, M., Citron, M., Schnabel, F., Schuss, A., Hajdu, S., Vinciguerra, V., Santella, R.M. Organochlorine compounds and the risk of breast cancer among women on Long Island, New York: The Long Island Breast Cancer Study Project. Cancer Epidemiol Biomarkers Prev. 2002;11(8):686-97.**

**Wolff, M.S., Britton, J.A., Wilson, V.P. Environmental risk factors for breast cancer among African-American women. Cancer. 2003;97(1 Suppl):289-310**

Gammon, M.D., Santella, R.M., Neugut, A.I., Eng, S.M., Teitelbaum, S.L., Paykin, A., Levin, B., Terry, M.B., Young, T., Wang, Q., Britton, J.A., Wolff, M.S., Stellman, S.D., Hatch, M., Kabat, G.C., Senie, R., Garbowski, G., Maffeo, C., Montalvan, P., Berkowitz, G.S., Kemeny, M., Citron, M., Schmabel, F., Schuss, A., Hajdu, S., Vinciguerra, V. (submitted). PAH-DNA adducts and the risk of breast cancer among women on Long Island.

Wolff, M.S., Berkowitz, G.S., Lapinski, R., Britton, J.A., Forman, J., Hochman, S., Kabat, G.C., Godbold, J., Larson, S. (submitted). Ethnic differences in onset of puberty and the influence of diet.

Britton, J.A., Wolff, M.S., Lapinski, R., Forman, J., Hochman, S., Kabat, G.C., Godbold, J., Larson, S., Berkowitz, G.X. (submitted). Characteristics of pubertal development in a multi-racial/ethnic population of nine-year old girls.

**DR. DANIEL DAVID (former trainee) - PAPERS:**

Montgomery, G.H., David, D., Winkel, G., Silverstein, J. H., Bovbjerg, D.H. The effectiveness of adjunctive hypnosis with surgical patients: A meta-analysis. Anesthesia & Analgesia. 2002; 94:1639-1645.

Montgomery, G.H., David, D., Goldfarb, A.B., Silverstein, J.H., Wertz, C.R., Birk, J.S., Bovbjerg, D.H. Sources of anticipatory distress among breast surgery patients. Journal of Behavioral Medicine. 2003;26:153-164.

David, D., Montgomery, G.H., Holdevici, I. Romanian norms for the Harvard Group Scale of Hypnotic Susceptibility, Form A. International Journal of Clinical and Experimental Hypnosis. 2003;51:51-56.

David, D., & Brown, R. (in press). Suggestibility and negative priming: Two replications studies. International Journal of Clinical and Experimental Hypnosis.

Montgomery, G.H., David, D., DiLorenzo, T., Erblich, J. (in press). Is hoping the same as expecting? Discrimination between hopes and response expectancies for nonvolitional outcomes. Personality and Individual Differences.

David, D., Moore, M., & Domuta, A. (in press). Romanian psychology on the international psychological scene: A preliminary critical and empirical approach. European Psychologist.

**DR. JENNIFER EGERT (former trainee) - PAPERS:**

Smith, M.Y., Egert, J.R., Winkel, G., Jacobson, J. The impact of PTSD on pain experience in persons with HIV/AIDS: A prospective study. Pain. 2002;98:9-17.

Egert, J.R., Keefe, F.J., Winer, E., Rimer, B. (submitted). Coping and social support as predictors of positive dimensions of psychological well-being among women who completed treatment for early stage breast cancer.

Egert, J.R., Keefe, F.J., Winer, E., Rimer, B. (submitted). Re-defining a "Good adjustment" to cancer: psychological well-being, coping and social support following breast cancer treatment.

Egert, J.R., Winer, E., Smith, M.Y., Rimer, B., Winkel, G., Keefe, F.J. (submitted). Psychological well-being, distress and quality of life following treatment for early stage breast cancer.

Smith, M.Y., Egert, J.R., Winkel, G., Jacobson, J. (submitted). Post-traumatic stress disorder and pain symptoms in persons with HIV/AIDS: A prospective study.

**DR. ANNE FATONE – POSTERS, PRESENTATIONS, ABSTRACTS AND PAPERS:**

Fatone, A., Jandorf, L., Modibo Baker, J., Brenner, B., Butts, G., Cornbill, R., Itzkowitz, S.H., Levin, M., Rothenberg, A., Sacks, H., Weeks, M., Redd, W.H. (submitted). East Harlem Partnership for Cancer Awareness (EHPCA): collaborative cancer screening and prevention research in an urban minority community.

Thompson, H., Wahl, E., Fatone, A., Brown, K., Kwate, N., Valdimarsdottir, H. (submitted). Increasing the readability of materials describing genetic risk for breast cancer: A constituent-involving approach to evaluation.

Fatone, A., Moadel, A., Foley, F., Fleming, M., Jandorf, L. Urban Voices: A qualitative analysis of quality of life issues as described by women of color who are breast cancer survivors. Poster presented at The Society of Behavioral Medicine, Salt Lake City, 2003.

**DR. JOSEPHINE GUEVARRA (former trainee) - PAPERS:**

Thompson, H.S., Valdimarsdottir, H.B., Guevarra, J.S., Duteau-Buck, C., Richmond-Avellaneda, C., Amarel, D., Godfrey, D., Brown, K., Offit, K. Psychosocial predictors of BRCA counseling and testing decisions among urban African American women. Cancer Epidemiol Biomarkers Prev. 2002;11:1579-1585

Guevarra, J.S., Tang, T.S., Valdimarsdottir, H.B., Freeman, H.P., Kwate, N.O., & Bovbjerg, D.H. (submitted). Acculturation and its relationship to smoking and breast self-examination frequency in African American women.

**DR. MARIA KANGAS – POSTERS, PRESENTATIONS, ABSTRACTS AND PAPERS:**

Kangas, M., & Bryant, R. A. (submitted). Correlates of acute stress disorder in cancer patients journal of traumatic stress.

Kangas, M., Henry, J.L., & Bryant, R.A. (submitted). The relationship between acute stress disorder and posttraumatic stress disorder following cancer.

**DR. YOUNGMEE KIM (former trainee) - PAPERS:**

Kim, Y., Roscoe, J.A., & Morrow, G. R. The effects of information and negative affect on severity of side effects from radiation therapy for prostate cancer. Support Care Cancer. 2002;10(5); 416-421.

Kim, Y., & Seidlitz, L. Spirituality moderates the effect of stress on emotional and physical adjustment. Personality and Individual Differences. 2002; 32, 1377-1390.

Kim, Y., & Morrow, G. R. Changes in family relationships affect the development of chemotherapy-related nausea symptoms. Support Care Cancer. 2003;11(3): 171-177.

Kim, Y., Deci, E. L., & Zuckerman, M. (in press). The self-regulation of withholding negative emotions: Development of a questionnaire. Educational and Psychological Measurement.

Kim, Y., Kasser, T., & Lee, H. (in press). Self-concept, aspiration, and well-being in Korea and the United States. Journal of Social Psychology.

Kim, Y., Valdimarsdottir, H.B., Bovbjerg, D.H. (in press). Family histories of breast cancer, coping styles and psychological adjustment. Journal of Behavioral Medicine.

Kim, Y., Valdimarsdottir, H. B., & Bovbjerg, D. H. (submitted). The moderating effects of coping on the psychological impact of having a family history of breast cancer.

Sheldon, K. M., Elliot, A. J., Ryan, R. M., Chirkov, V., Kim, Y., Wu, C. Demir M., & Sun Z. (submitted). Autonomy and collectivism: Complementary, not conflicting.

Kim, Y. (submitted). Specialized and fragmented cognitive concept on the self and romantic relationships.

Kim, Y. (submitted). Emotional and cognitive consequences of adult attachment: The mediating effect of the self.

Kim, Y., Sahler, O.J., Messauer, L., & Vattimo, C. (submitted). Parental adjustment in childhood cancer: Marital and occupational issues.

#### **DR. NAA OYO KWATE – POSTERS, PRESENTATIONS, ABSTRACTS AND PAPERS:**

Kwate, N.O. Race, socio-economic status, and breast cancer treatment and survival. Journal of the National Cancer Institute. 2002; 94(16), 1254.

Kwate, N.O. The projection of Eurocentrism in projective testing. In: African-centered Psychology: Culture-focusing for Multicultural Competence. 2003. D.A. Azibo, (Ed.). Durham: Carolina Academic Press.

Kwate, N.O., Valdimarsdottir, H.B., Guevarra, J.S., & Bovbjerg, D.H. (in press). Experiences of racist events have negative health consequences for African American women. Journal of the National Medical Association.

Kwate, N.O. (in press). The projection of eurocentrism in projective testing. African-centered Psychology. North Carolina Press.

Kwate, N.O. (in press). Cross-Validation of the Africentrism Scale. The Journal of Black Psychology.

Guevarra, J.S., Tang, T.S., Valdimarsdottir, H.B., Freeman, H.P., Kwate, N.O., & Bovbjerg, D.H. (submitted). Acculturation and its relationship to smoking and breast self-examination frequency in African American women.

Valdimarsdottir, H.B., Kwate, N.O., Thompson, H.S., Wahl, E., & Brown, K. Culturally-Tailored Counseling for BRCA1 and BRCA2: Participant Information Manual. Mount Sinai School of Medicine, 2002.

Experiences of racist events have negative health consequences for African American women. The 2002 Annual Society of Behavioral Medicine Meeting, Washington, DC The 34<sup>th</sup> Annual Convention of The Association of Black Psychologists, San Diego, CA 2002.

Walker, R., Cokley, K., Kwate, N.O., Thompson, S.N., Utsey, S.O. From antiquity to the present: The role of the new professional. (Panel Session). The 34<sup>th</sup> Annual Convention of The Association of Black Psychologists, San Diego, CA 2002

Kwate, N.O., Valdimarsdottir, H.B., Guevarra, J.S., & Bovbjerg, D.H. "Racism Affects African American Women's Health". The 2002 Annual Society of Behavioral Medicine Meeting, Washington, DC.

Kwate, N.O. Neo-colonialism, neo-minstrelsy, and neoplasms: Or, do racism and cultural identity affect African American health? (Invited lecture). Integrative and Behavioral Cardiology, Mount Sinai School of Medicine, March, 2003.

Kwate, N.O.A., Valdimarsdottir, H.B., Bovbjerg, D.H. Ethnic differences in etiological attributions for breast cancer among healthy African American and European American women. (Citation Paper). The 2003 Annual Society of Behavioral Medicine Meeting, Salt Lake City, Utah.



**DR. TRICIA TANG (former trainee) - PAPERS:**

Tang, T.S., Bozynski, M.E., Mitchell, J.M., Haftel, H.M., Vanston, S.A., Anderson, R.M. Are residents more comfortable than faculty members when addressing sociocultural diversity in medicine? Academic Medicine. 2003; 78(6): 629-633.

Tang, T.S., Fantone, J.C. Bozynski, M.E., Adams, B.S. Implementation and evaluation of an undergraduate Sociocultural Medicine Program. Academic Medicine. 2002;77(6):578-585.

Tang, T.S., White, C.B. Gruppen, L.D. Does Spirituality matter in patient care? Establishing relevance and generating skills. Academic Medicine. 2002;77(5):470-471.

Tang, T.S., Adams, B.S., Skye, E.P. Playing the role of a bioethics committee: creative approaches to teaching culture and bioethics. Academic Medicine. 2002;77(5):469-470.

Guevarra, J.S., Tang, T.S., Valdimarsdottir, H.B., Freeman, H.P., Kwate, N.O., & Bovbjerg, D.H. (submitted). Acculturation and its relationship to smoking and breast self-examination frequency in African American women.

**DR. KRISTIN TATROW – POSTERS, PRESENTATIONS, ABSTRACTS AND PAPERS:**

Tatrow, K. J., & Blanchard, E. B. Headache activity and psychological functioning in menstrual and non-menstrual headache sufferers. Headache Quarterly. 2002;13,11-18.

Tatrow, K., Blanchard, E. B., & Silverman, D. J. (in press). Post-traumatic headache: An exploratory treatment study.

Tatrow, K., Blanchard, E. B., Hickling, E. J., & Silverman, D. J. (in press). Post-traumatic headache: Biopsychosocial comparisons to multiple controls.

Tatrow, K., & Blanchard, E. B. (in press). Menstrual cycle effects on headache activity of tension-type headache: Preliminary data.

Tatrow, K., Montgomery, G. H., Avellino, M., & Bovbjerg, D. H. (submitted). Activity and sleep contribute to levels of anticipatory distress in breast surgery patients.

Tatrow, K., Blanchard, E. B., Hickling, E. J., & Silverman, D. (2002, November). Posttraumatic stress disorder in posttraumatic headache sufferers. Poster session presented at the annual meeting of the Association for Advancement of Behavior Therapy, Reno, NV.

Gusmano, R., Tatrow, K., Rowell, D., Keefer, L., Barton, K., & Blanchard, E. B. (2002, November). Perceived stress and chronic headache: A prospective study. Poster session presented at the annual meeting of the Association for Advancement of Behavior Therapy, Reno, NV.

Tatrow, K., Blanchard, E. B., Hickling, E. J., & Silverman, D. (2002, November). Posttraumatic headache and memory impairment. Poster session presented at the annual meeting of the Association for Advancement of Behavior Therapy, Reno, NV.

Tatrow, K., Blanchard, E. B., Hickling, E. J., & Silverman, D. (2002, November). Alleviating headache pain in posttraumatic headache sufferers. Poster session presented at the annual meeting of the Association for Advancement of Behavior Therapy, Reno, NV.

Tatrow, K., Montgomery, G. H., Erlich, M. D., Avellino, M. D., Birk, J. S., & Bovbjerg, D. H. (2003, August). The impact of surgery and family histories of breast cancer on distress. In K. Tatrow (Chair), Recent findings in cancer research. Symposium to be conducted at the annual meeting of the American Psychological Association, Toronto, Ontario, CANADA.

Montgomery, G. H., Tatrow, K., David, D., Avellino, M. D., Birk, J. S., & Bovbjerg, D. H. (2003, August). Pre-surgery expectancies and distress predict side-effects of breast cancer surgery. In K. Tatrow (Chair), Recent findings in cancer research. Symposium to be conducted at the annual meeting of the American Psychological Association, Toronto, Ontario, CANADA

Avellino, M. D., Tatrow, K., Montgomery, G. H., & Bovbjerg, D. H. (2003, August). Exercise and sleep predict pre-surgical distress in breast surgery patients. Poster to be presented at the annual meeting of the American Psychological Association, Toronto, Ontario, CANADA.

## **9. CONCLUSIONS:**

During the past year, we have continued to successfully complete the Technical Objectives of the Postdoctoral Training Program in Biobehavioral Breast Cancer Research:

**Aim 1.** To provide postgraduate trainees a broad-based intellectual background needed to conduct interdisciplinary biobehavioral breast cancer research through structured didactic training (e.g., Core Curriculum Lecture Series, Advanced Seminars) and informal interactions with the Training Faculty and other active researchers.

**Aim 2.** To teach Trainees interdisciplinary research skills through hands-on participation in ongoing federally-funded breast cancer research programs of the Training Faculty and by having Trainees develop and conduct their own related biobehavioral research projects with the guidance of their research Mentors.

**Aim 3.** To foster the development of Trainees' independent research careers in biobehavioral breast cancer research through both formal instruction and direct experience with writing research papers and grants, under the direct tutelage of their Mentors.

During the next year, (assuming approval of a requested no cost extension of the funded grant), we propose to continue the Program for those Trainees who have not yet completed their full training period. Because several previous Trainees have demonstrated mastery of the elements of the Program and found positions in less than the standard two-year training period, we have been able to make the program available to more Trainees than were originally envisioned. Entering new Trainees into those slots as they open has allowed us to maximize the impact of our Program (see Technical Objectives). While this approach desynchronizes the periods of support for our Trainees (i.e., start dates vary), the ongoing training program accommodates such variability without difficulty. Our goal for the next year will therefore be to continue the Program and to make plans for the transition to alternative sources of funding (e.g., NCI) to provide support in subsequent years.

Ethnic differences in etiological attributions for breast cancer among healthy African American and European American women

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Anecdotal evidence suggests that African American women's attributions about breast cancer may differ from European American women (e.g., "breast cancer is caused by a blow to the breast"). However, empirical studies are lacking. If African American women have different attributions, strategies for cancer prevention and control will need to be appropriately tailored. The present study examined attributions about breast cancer made by a sample of healthy African American and European American women working in a medical center, with and without a family history of cancer. The sample included 194 women (74 African American, 120 European American), with a mean age of 39.2. Participants completed a modified version of the Illness Perception Questionnaire, which included some additional items about emotional and other causes. Overall, women were most likely to attribute the development of breast cancer to genetics, "no one", environmental poisons, diet, personal behavior and stress. European American women were more likely to attribute breast cancer to the environment ( $p < .01$ ), heredity ( $p < .001$ ) and chance ( $p < .05$ ), while African American women were more likely to list blow to the breast ( $p < .01$ ), and personal behavior ( $p < .05$ ). There were no differences between women with or without a family history of cancer. Results suggest that culturally-targeted interventions for breast cancer awareness and screening may be beneficial to African American women.

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## Increasing the Readability of Materials Describing Genetic Risk for

### Breast Cancer: A Constituent-Involving Approach to Evaluation

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Increasing the Readability of Materials Describing Genetic Risk for  
Breast Cancer: A Constituent-Involving Approach to Evaluation

**Abstract**

**Background:** Although a significant portion of the U.S. population reads at or below a 5<sup>th</sup>-grade level, most printed cancer education materials require a much higher level of literacy. Increased focus on readability is especially important in cancer genetics materials as adequate knowledge of the consequences of genetic risk assessment is essential for informed consent. The goal of the current project was to evaluate efforts to increase the readability of a manual describing genetic risk for breast cancer.

**Methods:** The project included three phases. In the pre-evaluation phase, research team members applied recommended strategies for increasing readability in an initial effort to revise an existing manual. Evaluation Phase I was based on a rapid focus group of breast cancer survivors asked to provide feedback on images to be included in the revised manual. Evaluation Phase II was based on obtaining ratings from adult learners with low literacy skills who evaluated the readability, format, and appearance of the revised manual.

**Results and Conclusions:** The evaluation phases provided the research team with critical feedback that guided further manual revision. The efforts of the current project may serve as a model for other researchers developing cancer education materials. A constituent-involving approach can help to ensure that materials will not only be understood by a target audience and but benefit that audience in a meaningful and practical way.

## Introduction

Literacy is a critical yet often overlooked issue in the development and dissemination of printed cancer education materials. Department of Education National Adult Literacy Survey results revealed that approximately 20-25% of the U.S. adult population reads at or below a 5<sup>th</sup>-grade level and lacks the basic reading skills that would enable them to read and understand directions on a map or instructions on a medication bottle (1) (2). The inability to fully understand written material reduces the quality of information obtained through reading and has been found to affect the quality of health care experiences. Low reading comprehension is associated with lower recall of health care information and lower satisfaction with the communication of such information (1). It is not surprising, then, that low literacy levels are consistently associated with poorer health status (3) (4). Although the association between literacy level and cancer-related outcomes has not been examined specifically, reviews have revealed that most cancer education materials are written at a 10<sup>th</sup>-grade level or higher (1) which would make such materials too difficult for a significant portion of the population to understand. As a result, there has been a growing emphasis on efforts to increase the readability of printed cancer-related information.

Little attention has also been paid to the literacy level required by materials developed for individuals at high risk for developing breast cancer due to their family history of the disease. It is estimated that between 5-10% of breast cancer cases are due to mutations in two genes, BRCA1 and BRCA2 (5;6) and BRCA1/2 testing is now available commercially. In order to make an informed decision, individuals need to understand complex genetic information as well as the potential negative consequences of testing (e.g., increased worry about one's health status and the health of family members, feelings of stigma, anticipation of negative emotional reactions, and possible insurance or employment

discrimination) (7-10). This may be particularly challenging as studies of both high-risk and average-risk individuals reveal that genetics knowledge or self-reported awareness of genetics is limited (9-15).

Richards and Ponder (16) assert that a general "genetic literacy" is a prerequisite for appropriate use of genetic tests, since testing must be preceded by informed consent in which the individual indicates that she or he has sufficient information about the testing process and the implications of test results (17). Although a review of the readability of patient-directed cancer genetics materials does not appear in the literature, Gribble (18) determined the readability of informed consent documents for BRCA1/2 testing obtained from several research institutions. On average, these documents were written at a grade level one year beyond high-school graduation and had reading ease scores similar to those of academic journals. These results are indicative of what has been referred to as a "readability gap" (18) between the language of cancer genetics materials and the low literacy skills of many people. This readability gap may be reduced by creating materials containing simple, straightforward language that are more likely to increase overall genetics literacy as well as one's knowledge of cancer genetics, comprehension of the consequences of testing, and the provision of truly informed consent.

To date, there is little published work on strategies to increase the readability of patient-directed cancer genetics materials. However, at least two approaches have been described for printed health care materials in general. The first approach involves the tailoring of such materials based upon assessment of the reading level of the individual receiving the materials (19). Tools available for individual assessment of literacy and comprehension include the Rapid Estimate of Adult Literacy in Medicine (REALM) (20) and the Test of Functional Health Literacy in Adults (TOFHLA) (21). Following assessment, an individual could receive educational materials specific to his or her reading level. This individually tailored approach has been used in a range of clinical settings, but may not be practical as it is potentially time-intensive in terms of both assessment as well as material development. The second

and more widely recommended approach involves creating materials that may be read and understood regardless of reading level.

It is the latter approach that guided the current project which focused on increasing the readability of an existing manual describing genetic risk for breast cancer. This effort was part of an ongoing research project, funded by the Department of Defense, at Mount Sinai School of Medicine (MSSM) called TACT (Talking About Counseling and Testing). The primary aim of TACT is to evaluate the impact of culturally targeted genetic counseling session versus a standard counseling session on decisions to undergo BRCA1/2 testing among African American breast cancer patients. As part of this aim, it was necessary to develop supplementary printed materials that review the basic content of the counseling sessions. These materials would then be provided to TACT participants at the end of their counseling session to read privately and at their own pace. The development of these materials was based on a revision of an existing patient manual obtained through a separate research study conducted at both the Lombardi Cancer Center at Georgetown University and MSSM called PATH (Personal Aid to Health). This manual contains 26 pages of breast cancer genetics information, followed by an additional 13 pages of resources. The manual begins with an overview of the PATH study and provides background information on risk factors for breast and ovarian cancer. It goes on to review the inheritance of cancer susceptibility including a discussion of breast cancer susceptibility genes (specifically, BRCA1 and BRCA2) and the cancer risks associated with alterations in these genes. The manual also reviews the process of genetic testing and presents benefits and limitations of genetic testing. Finally, the manual includes a discussion of appropriate cancer screening and risk reduction options for breast and ovarian cancer. Upon review of the PATH manual, the TACT research team decided it was necessary to revise the manual because it was written at a considerably sophisticated level, was quite dense in terms of written text, and had few pictures that enhanced comprehension of the text. Based on the findings documenting the prevalence of low literacy levels in the U.S., the TACT team was concerned that the

original PATH manual would be inappropriate for many TACT participants. It is important to note again that all TACT participants are African American women and that while the majority of those with low literacy skills are white, this problem is disproportionately observed among African Americans and other underserved ethnocultural groups (22).

The revision of the PATH manual included several phases. In the pre-evaluation phase, the TACT research team completed an initial revision of the PATH manual by applying widely recommended strategies described by literacy researchers to increase the readability of health care materials. In the next phases, the TACT team employed a constituent-involving approach to evaluation. Kreuter et al. (23) have described a constituent-involving approach as a method of increasing the cultural appropriateness of health interventions. This approach draws directly upon experience and expertise of members of the target population. Thus, in the evaluation phases the TACT team sought the participation of two groups that were similar to the target population of African American breast cancer patients, of whom a portion are expected to have low literacy skills. Evaluation Phase I was based on a rapid focus group of breast cancer survivors in order to obtain feedback on the images that were included as part of the revision. Evaluation Phase II was based on a collaboration with a reading and writing class for adult learners with low literacy skills to obtain feedback on both the images and text of the revised manual. The evaluation phases were components of educational efforts in both constituent groups to increase awareness of genetic risk for breast cancer.

### **Pre-Evaluation Phase: Application of Recommended Strategies to Increase Readability**

Several authors recommend useful strategies for creating printed health-related materials appropriate for a wide range of reading levels (1) (24-26). These strategies include: the use of large font; use of one to two syllable words whenever possible; use of headings to introduce new ideas; partitioning of more

complex information into small components; providing visual images to accompany each partitioned component; highlighting of important information with bold or italic lettering; defining and using phonetic pronunciation for difficult words; limited use of tables and graphs; and increased use of white space on a page. In this first phase of the manual revision, the TACT team applied many of these strategies to the original PATH manual. Described below is the use of three strategies: word substitution and limiting of sentence length, increasing comprehension of difficult words, and the use of analogies as examples.

**Word Substitution and Limiting of Sentence Length:** Each TACT research team member was assigned a section of the manual in order to identify words that were not commonly used and with which participants might have difficulty. Whenever possible, the team member substituted the more difficult word with a simpler word. For example, the word "individual" was replaced by "person" or "woman." In most instances, the word "risk" was substituted with "chance." In another example involving the revision of a section heading the, PATH heading, "Inheritance of Cancer Susceptibility" was revised as "Passing Down a Greater Chance of Cancer". The TACT team also attempted to shorten sentences whenever possible. For example, the PATH heading, "Estimated Cancer Risks Associated with BRCA1 and BRCA2 Alterations" was revised as "What does it mean if I have a BRCA Mutation?" The strategies of word substitution and limitation of sentence length were both applied to revising this particular heading and also helped change the tone of the manual. Instead of maintaining the clinical tone of the PATH manual, the TACT team opted for a more conversational tone. Often, a statement was revised as a question as the TACT team attempted to anticipate questions that a reader might have at different points in reading the manual. For example, the sentence "The causes of these diseases [breast and ovarian cancer] cannot be pinpointed to a single factor" was replaced with 2 shorter sentences: "But what causes these diseases? It is not one single thing." These modifications not only limited sentence length but promoted a less clinical tone.

**Comprehension of Difficult Words:** In some instances, word substitution was not possible because there were not many alternative words. This was the case with many words or terms specific to genetics or preventive care, such as *dominant inheritance*, *variants*, *sequencing*, and *prophylactic mastectomy*. In some cases, the TACT research team thought it was more instructive to retain a word if it was commonly used by genetics professionals. Difficult words that were retained were printed in boldface type followed by definitions in the text. Also, in the beginning of the manual, readers were told that all words in boldface could be found in a glossary at the end of the manual. The glossary included the pronunciation of the word and, in many cases, a more detailed definition.

**Use of analogies as examples:** Providing clear and relatively simple examples of genetic risk concepts proved to be one of the most challenging parts of the revision of the PATH manual. The use of analogies has been recommended as a way of clarifying concepts (26) and wherever possible, the TACT team used analogies that would be familiar to the manual's target audience. One example of concept substitution was in the manual's explanation of the meaning of BRCA1/2 test results. Such test results were explained in the revised manual using the analogy of a train ride, because this situation is particularly relevant to the daily experience of the urban population from which the majority of participants would be recruited. In this analogy, readers were asked to imagine that they were taking an express train to make an appointment on Main Street. Variants of unknown significance were described in three ways. A portion of the text of this analogy is provided below:

*Let's use an example to understand this [variant result of uncertain significance]. Let's say you have an appointment on Main Street, and you have to arrive on time. To get there you take the T train, which always goes express.*



*You know that if the T train goes express to Main Street, you will make it to your appointment on time. But imagine 3 different things that could happen to the train. In each situation, you are not sure if you will arrive on time. If this were a genetic test, these changes would be of "unclear significance". Let's compare the train examples to genetic test results.*

*The train is delayed: The conductor announces, "We hope to be moving shortly." What does that mean? Are you only going to be delayed a few minutes? Or is the train going to be stuck for a half a hour? This result means there is a change and this change could mean something, but we're not sure." In genetic testing, this would get the label variant of unknown significance.*

*The train goes slower: The conductor announces, "The T train will be running local to Main Street." You can't say for sure what time you will arrive, but you will probably make it to your appointment on time. So this result means, "this change probably doesn't mean anything." In genetic testing, this would get the label variant of unknown significance, favor polymorphism.*

*The train changes its route: the conductor announces, "The T train will be skipping the Main Street stop. Passengers must ride to Central Street and go backwards." Here, the conductor has said that the train won't be stopping at Main Street at all! You feel pretty sure that you are going to be late for your appointment now. So, this result means, "there is a change here, and most likely it means something – we doubt that it means nothing." In genetic testing, this would get the label variant of unknown significance, favor deleterious.*

**Impact of Applied Strategies:** After the initial revision, the readability of the manual was assessed using quantitative methods. Word difficulty and sentence length are key elements of the Flesch Readability Test which assesses reading ease. This assessment is based on a formula that yields a score

of 0 (extremely difficult to read/average sentence length is 37 words, average word > 2 syllables) to 100 (very easy to read/average sentence length is 12 words, no words of more than two syllables). The Flesch Reading Ease score of the manual after revision was 64.8. Also assessed was the grade level of the language of the revised manual through the Flesch-Kincaid Grade Level which is a function of the average length of sentences in a text and the average number of syllables per word. The Flesch-Kincaid Grade Level of the revised manual was 7.7. Therefore, in spite of initial efforts, the literacy level required by the revised manual was quite high. However, it was possible that readability scores were inflated by the retention of genetics-specific words that tended to be multi-syllabic and more advanced, and that, overall, the reading level required by the manual was lower than indicated. This finding confirmed the need for constituent evaluation.

#### **Evaluation Phase I: Rapid Focus Group Evaluation of Images in Manual**

A key part of the revision of the manual was to develop and include new images that would be easily processed and interpreted. Most of these images were designed by a TACT research team member (N.O.K.) as cartoons that accompanied specific text and demonstrated various genetic concepts. Once new images were included in the revised manual, the TACT team sought feedback to determine if, in fact, the new images were more easily interpreted, thereby increasing comprehension of the text. An additional concern was whether cartoon images were appropriate in tone for the manual's target audience of breast cancer patients for whom risk of recurrence as well as family members' breast cancer risk may be a weighty topic. Researchers have recommended that developers of print materials use adult-looking visuals and warn against childish or "cutesy" visuals that may make the materials appear less credible to an adult (26).

**Participants:** The focus group included seven female breast cancer survivors who were designated as Patient Advocates for Research Participation (PARPs). These survivors recruit breast cancer patients for a separate, ongoing, large-scale case-control study at MSSM in an effort to increase ethnocultural diversity among individuals recruited for research. Participants were three African American survivors, three white survivors, and one Latina survivor, ranging in age from 45 to 54 years.

**Procedures:** In accordance with the recommended strategies for increasing readability, the TACT team attempted to limit the use of tables and graphs in the revised manual and increased the number of pictures that accompanied different sections of the manual. The original manual included three tables and four pictures. The revised manual had only one graph and seven pictures. The focus group was moderated by two members of the TACT team: certified genetic counselor (K.B.) and a clinical psychologist (H.S.T.). The focus group was specifically a rapid focus group (27) in that it was adapted to accommodate emerging or immediate situations or opportunities. In this instance, the immediate opportunity was a scheduled monthly meeting of PARP recruiters. In a rapid focus group, questions are narrow in breadth, specific in focus, group discussion is limited, and moderator follow-up is brief.

First, the moderators introduced themselves, and the primary objectives of the TACT project were presented. Next, the objective of the rapid focus group was presented. Participants were informed that a manual describing genetic risk for breast and ovarian cancer was being revised and specific feedback on the manual's images was desired. Participants were told that because the manual was intended for breast cancer patients, their opinions as breast cancer survivors were desired. Each woman was presented with photocopies of both original and new images. The images were also reproduced on transparencies for overhead projection. As each image was displayed, a brief explanation of the image was provided by the genetic counselor. Both moderators then asked whether the image appeared

consistent with the explanation provided. Participants were also asked for their general opinions about the quality, clarity, and appropriateness of the images.

**Results:** Participants provided feedback for each of the eight images. Responses to 5 of these images are reported here. In most instances, participants were asked to compare the original image in the PATH manual to the new image in the revised manual developed by the TACT team. In the first comparison, Image 1 (original image) was a photographic reproduction of chromosomal pairs that was to be replaced by Image 2 (new image), a much simpler drawing of one pair of chromosomes that were anthropomorphized by giving them eyes, mouths and arms. In response to Image 1, one respondent noted, "I don't know what that's about." However, other participants felt that Image 1 was more informative than Image 2. One participant stated, "[Image 1] shows more of a whole picture to me." In comparing Image 1 to Image 2, another participants stated, "Number 1 looks like it has parts to it but number 2 doesn't. I'm fascinated with the first one." Responses to Image 2 were generally not positive. The human elements of the chromosome cartoon appeared to distract participants from concept it was trying to convey. One participant stated, "Does it represent a male or a female?" while another participant stated, "Something like this would insult my intelligence."

Image 3 was a new image created for the revised manual to demonstrate the concept of genetic dominance and had no original image to which it could be compared. In this cartoon, one anthropomorphized mutated gene appeared to dominate a conversation with a normal gene. The mutated gene had a hand placed over the mouth of the normal gene, which had annoyed expression on its face. In general, participants thought that this image was a clever and amusing way to explain dominance on a genetic level. However, they felt that some of the characteristics of the cartoon genes could be altered in order to explain this more clearly. One participant responded, "The normal gene looks too cross to be dominated. He doesn't look submissive at all."

Participants were also asked to compare Images 4 (original image; see Figure 1) and 5 (new image; see Figure 2), both of which were intended to demonstrate dominant inheritance of a cancer susceptibility gene. Image 4 was the original image to be replaced and showed pairs of ovals representing genes. Two gene pairs were at the top of the page and represented the genes of parents while four gene pairs below showed the possible combinations of the parental genes for offspring in order to illustrate the chances that offspring would inherit a nonfunctioning cancer susceptibility gene. A series of lines connected the parent genes to offspring genes. Image 5 was similar to Image 4 in that the genes were represented by pairs of ovals. However, in Image 5, the maternal, paternal, and offspring genes were given eyes and a mouth, and were pictured alongside illustrated human faces. Image 4, the more standard image used in genetic counseling, was unclear to most of the participants because the possible combinations of maternal and paternal gene pairs resulted in four potential pairs. Most participants thought the four pairs represented four different offspring, when, in fact, they represented four potential pairs for one offspring. In spite of this misinterpretation, one participant reported that Image 4 was clearer, "...because of the lines going from one to the other." However, there was stronger group preference for Image 5. One participant said of Image 5, "It's very detailed but simple. It does a good job of explaining it."

**Implications for Manual Revision:** Rapid focus group methodology enabled the TACT research team to obtain specific information regarding the utility and appropriateness of images for the revised manual. This method proved effective as the TACT team was able to incorporate feedback immediately by changing images or eliminating them from the manual altogether. For the manual revision, it was particularly important for the TACT team to know whether the cartoons and other illustrations were appropriate for its intended audience of breast cancer patients by determining whether they were: a) effective in increasing comprehension of genetic concepts described in the text, b) clear and informative

without being too simplistic, and c) inoffensive in light of some humorous elements. The focus group participants provided specific feedback and productively addressed these issues.

### **Evaluation Phase II: Evaluation by Adult Learners with Low Literacy Skills**

Once a draft of the revised manual including images was complete, feedback was sought from another group of constituents: adults with low literacy skills. Towards this end, the TACT team collaborated with a literacy program based in Harlem, New York City that was sponsored by the local library system. The goal of this program is to serve adults who are non-readers or who are beginning readers and writers by providing instruction in small groups, facilitated by volunteer tutors who are recruited, trained, and supported by professional staff members. Review of the revised manual was consistent with the literacy program's goal of general health education.

**Participants:** Five participants reviewed the revised manual (3 male, 2 female) with an age range of 27 – 55 years. All participants were African American and were students in the literacy program, attending sessions at the library twice a week.

**Procedures:** Copies of the revised manual were submitted to the literacy program. Each copy began with instructions informing participants of the purpose of the booklet and that they were being asked to read a section of the manual to make sure that it is “easy to understand and the language is down-to-earth.” The manual was divided into sections by page number and participants were asked to select one section for review. Through an agreement with the leadership of the literacy program, participants were asked to review the manual during class time under the guidance of program tutors. Participants were also asked to complete a 6-item evaluation of the manual. These items, presented in Table 1, were

adapted from evaluation questions developed by Guidry and colleagues (25). Participants were also encouraged to provide general comments about the manual content.

**Results:** All five participants reviewed the first six pages of the manual. These pages contained sections discussing the major risk factors for breast and ovarian cancer and an introduction to genetics. Four of the five participants agreed that the information was presented in a way that was easy to understand and follow, that the font was easy to read, and that images in the manual were appealing. Additionally, all participants agreed that the print size was easy to read. However, not all responses were generally positive. When asked how well they understood the meaning of all the words used in the booklet, all participants reported "a little" or "not at all." Also, when asked that how much they liked the way the materials looked, four of the five participants reported "a little" or "not at all."

**Implications for Manual Revision:** The evaluations of these adult learners provided vital information regarding the effectiveness of applied strategies to increase the readability of the manual. Although these participants agreed that the format and presentation of this section of the manual facilitated reading ease and comprehension, they largely reported that many words were difficult to understand. As in the pre-evaluation phase, it was unclear whether lack of understanding was due to the use of words specific to genetics but clearly defined, or whether there were other, more common words that could have been substituted. In any case, this feedback suggested to the TACT team that the use of genetic jargon might be reduced. Furthermore, participants generally did not like the way the materials looked. This may have been due to the fact that the manual was not "in color" and did not have polished look of many educational materials with which they may be familiar. This is unclear as specific feedback on these aspects was not provided. Although feedback was somewhat limited, it provided the TACT team with an indication of how others with low reading ability might respond to the revised manual and warranted continued efforts to improve readability as well as the "look" of the manual.

## Discussion

Literacy is an often neglected issue in the development of printed cancer education materials. This is disturbing as approximately one-quarter of the U.S. population has fairly low literacy skills or is functionally illiterate. The use of strategies to increase the readability of cancer genetics materials is a particularly important endeavor given the low awareness of cancer genetics reported by diverse samples and the high importance of informed consent in the genetic counseling and testing process. The project reported here describes efforts to apply a constituent-involving approach to a readability evaluation of a revised breast cancer genetics manual.

In the pre-evaluation phase, a wide range of strategies were applied in order to increase the manual's readability, including word substitution and limiting of sentence length, the inclusion of definitions of difficult words (in the text and in a separate glossary), and the increased use of analogies. Even after application of these strategies, quantitative analysis revealed that the reading level required by the manual remained quite high. However, as this may have been due to the retention of a limited number of words specific to genetic risk that are not commonly used, constituent evaluation was sought.

The first set of constituents were breast cancer survivors who gave feedback during a rapid focus group. Their responses informed the TACT team of the extent to which images included in the revised manual enhanced comprehension of the text and were appropriate in tone for women who are recent breast cancer patients. This focus group proved to be an efficient way of obtaining detailed feedback that enabled the TACT team to make decisions regarding which images to retain, eliminate or modify. The second set of constituents were African American adult learners with low literacy skills. By obtaining ratings of materials from adult learners, the research team obtained specific evaluation of the manual's



presentation, format, appearance and word difficulty. These ratings revealed that the adult learners had the most difficulty with word comprehension, suggesting to the TACT team that use of words specific to genetics might be reduced, even though their use might be of educational benefit.

Overall, a constituent-involving approach to evaluating the readability of the breast cancer genetics manual proved to be a viable strategy and may serve as a model for similar projects. There are several advantages to the constituent-involving approach. First, it is likely that the TACT team is similar to the staff of most research teams developing patient-directed cancer materials in that team members are highly educated and possess extensive knowledge of the cancer topic. These factors may lead to researchers to underestimate the complexity of that topic and may limit researchers' ability to assume the perspective of one who is largely unfamiliar with that topic. This is relevant to literacy issues because an individual with low prior knowledge of a topic may have great difficulty comprehending written information about the topic, even when his or her literacy level is adequate. Constituent evaluation has the potential to identify areas in which further explanation and clarification is necessary. A second advantage to the constituent-involving approach is that constituents may generate insights about educational materials that are not apparent to researchers. For example, in the focus group evaluation of manual images, participants voiced a preference for a representation of chromosomal pairs that the TACT team thought would be overwhelming and, ultimately, uninformative. Although the TACT team expected that participants would prefer the simpler representation, participants appreciated the complexity of the chromosomal pairs, indicating that it provided them with a more comprehensive view of the chromosomal environment. These responses suggested to the TACT team that although images should not be so detailed that they are confusing, detailed images can also convey a broader context that readers may find enlightening.

A third advantage of the constituent-involving approach to evaluation is that it is consistent with a participatory research model. This participatory model stresses substantive participation by community members in all phases of the research process; seeks to instill the values and perspectives of the community; and ensures that research benefits the community (28). According to this conceptualization, a participatory approach to research is necessarily a constituent-involving approach. In terms of addressing literacy issues, a participatory approach encourages the building of partnerships between researchers and community members that not only serve the interests of the researchers by providing access to populations and communities, but also meets community needs by providing reliable and up-to-date source of cancer information and related research findings. As was already mentioned, the goal of the TACT team was not only to evaluate readability but to present the evaluation in a context that increased awareness of genetic risk for cancer.

Although community members were not involved in all phases of the TACT readability project, the TACT team successfully collaborated with constituent groups of laypeople that were enthusiastic about participation in the readability evaluation and reported that they valued the cancer risk information they acquired through their participation. Other researchers developing cancer education materials may replicate this collaboration by identifying literacy programs, cancer patient/survivor networks and other community-based organizations that are open to forming partnerships to increase cancer awareness and knowledge in the community. Such partnerships will not only increase the effectiveness of the educational materials being created, but also ensure that these materials are truly appropriate for their target audience and contain information that may be practically applied to cancer-related decisions and experiences.

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Table 1. Items administered to adult learners.

1. The information was presented in a way that was easy to understand and follow.
2. The print size was easy to read.
3. The font or print style was easy to read.
4. The booklet had appealing pictures.
5. How well did you feel you understood the meaning of all the words used in the booklet.
6. How much did you like the way the materials looked?

Figure 1. Image 4 evaluated by a focus group of breast cancer survivors.

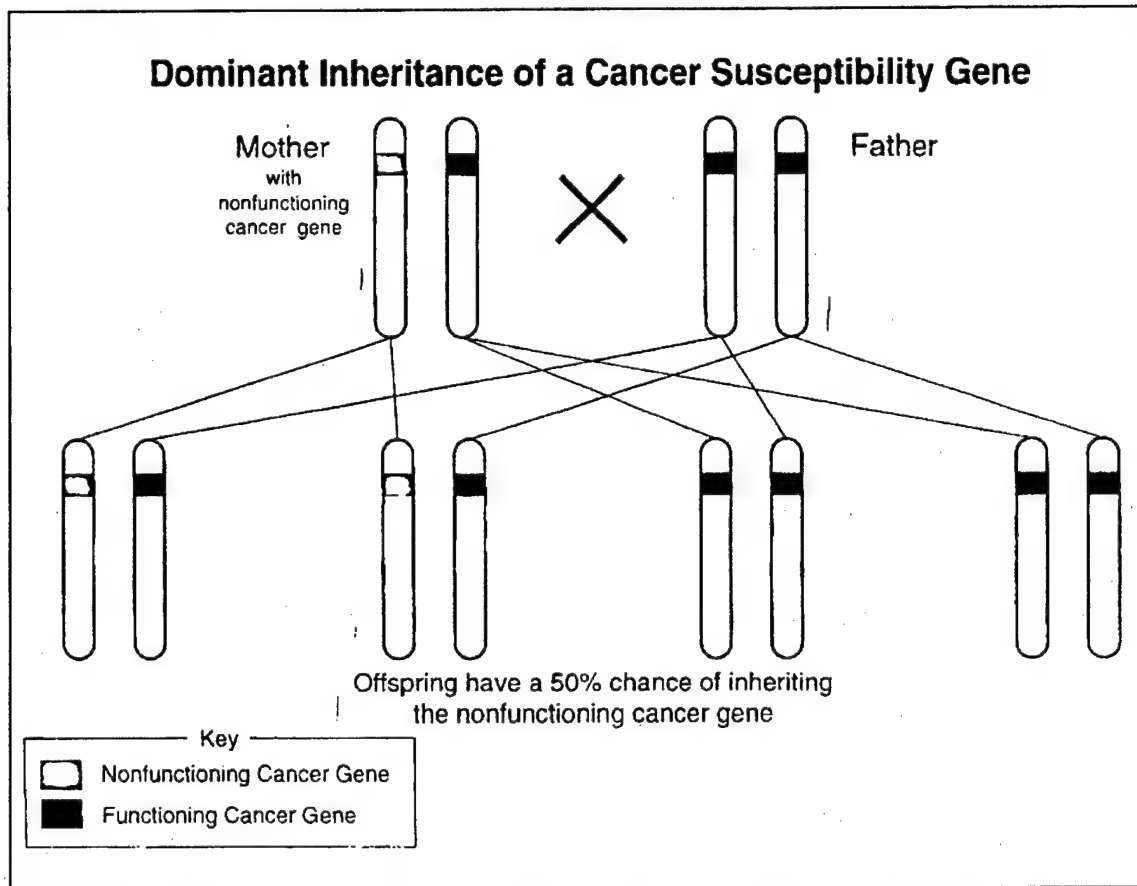
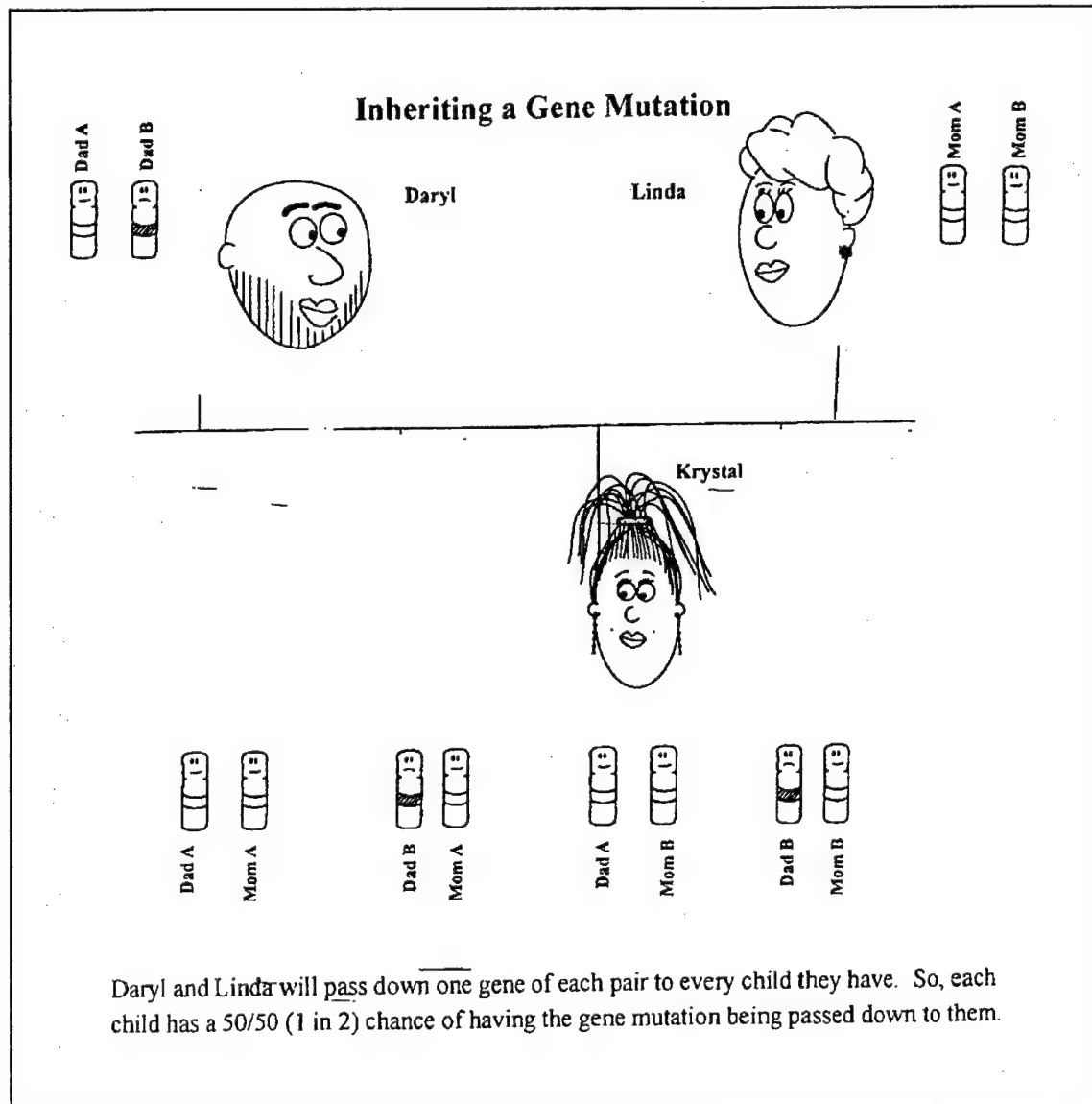


Figure 2: Image 5 evaluated by a focus group of breast cancer survivors.





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Experiences of Racist Events Are Associated With Negative Health Consequences for African  
American Women

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This study investigated whether experiences of racist events were related to psychological distress, negative health behaviors, and health problems. Participants were 71 African American women (mean age 44.4) who were recruited from an urban cancer screening clinic as part of a larger longitudinal study on familial risk of breast cancer. Participants completed three study assessments, approximately one month apart, and data were collected via self-report.

Correlational analyses revealed that past year and lifetime racism were both related to psychological distress. Among smokers and drinkers, past year racism was positively correlated with number of cigarettes and drinks consumed. Lifetime racism was negatively related to perceived health, and positively related to lifetime history of physical disease and frequency of recent common colds. Analyses using a general linear model revealed that these relationships were largely unaccounted for by other variables. In addition, demographic variables such as income and education were not related to experiences of racism. The results suggest that racism can be detrimental to African American's well being and should be investigated in health disparities research.

**KEY WORDS:** Racism, African American, Health Disparities, Chronic Stress

Numerous authors have commented on the ways in which longstanding racism in American society affects African Americans (1-10). A wide-ranging literature reveals that African Americans face denigrating images of themselves and their culture in the dominant society, are subjected to discrimination on institutional levels, and experience acts of prejudice (which may include physical violence) on an individual level (11-21). Moreover, the insidious nature of racism means that African Americans from varied backgrounds are affected (22-24). As a result, racism has been conceptualized as a chronic stressor in the lives of African Americans (25). The well documented health disparities between African Americans and European Americans in the United States (26-30) may be due, in part, to experiences with racism.

If racism represents a chronic stressor, the literature on the effects of chronic stress would suggest that it could have an adverse effect on both the mental and physical health of African Americans (31). As yet, however, little research has examined how experiences of racism may affect health outcomes. A few studies have provided evidence of a relationship between racism and mental health. For example, data from the National Survey of Black Americans showed that perceptions of racism and racial discrimination were associated with poorer mental health (32). In addition, discrimination has been shown to be related to lower levels of perceived mastery and higher levels of psychological distress (33, 34). Other studies report a relationship between experienced racism and intrusive thoughts about the racist event (35). These studies are likely to have underestimated the extent of the problem, because they utilized single-item assessments of racism, and this approach tends to underestimate discrimination (36).

For physical health, the literature on the effect of racism is more sparse (37, 38). In population samples, one recent study found that among a group of varied ethnicities, perceived

racism was related to poor self-perceived health status (39). An association between discrimination and cardiovascular outcomes has been reported, although not in a dose-response relationship (40, 41). Some authors have offered theoretical models of how racism might lead to chronic illnesses such as prostate cancer (42), but researchers have yet to investigate how these models bear out in practice.

Given that psychological stressors affect health behaviors, some investigations have studied how racism relates to health behaviors. Two studies (43, 44) examined the association between racism and smoking. The data shows that African Americans who experience more racial discrimination smoke more. Another study (45) found that transit workers of varied ethnicity who reported higher discrimination also reported more drinks per month, heavy drinking, and alcohol dependence than those who reported less discrimination.

The present study sought to build upon the current evidence by examining the role of experienced racism in psychological adjustment and physical health. Our investigation is undergirded by the biopsychosocial model proposed by Clark et. al (25), wherein the perception of racism is hypothesized to lead to adverse health outcomes through psychobiological stress responses, or negative health behaviors. More specifically, we looked at psychological distress, negative health behaviors (drinking, smoking), and health problems (perceived health, frequency of lifetime illness, and frequency of common colds). We hypothesized that higher perceived levels of racist events would be positively related to drinking and smoking behavior. In addition, because chronic stress has been found to be negatively related to physical health and the common cold (46-49), we hypothesized that racist events would also be positively related to perceived health, lifetime history of disease and the common cold.

## Methods

### Study design and sample

The data were gathered as part of a larger longitudinal investigation of women with different levels of familial risk for breast cancer. However, because including family history of breast cancer as a covariate in preliminary analyses did not alter the significant effects reported below, it was not included in the final analyses.

Participants were recruited from an urban cancer screening clinic (The Breast Examination Center of Harlem) that provides comprehensive diagnostic screening services to members of the Harlem community. All services are provided at no out of pocket expense to the client. Ninety-seven percent of the clinic's clientele is Black or Latina, and at the time data was collected for this study, the staff was 95% Black or Latino(a).

The sample was comprised of 71 African American women with a mean age of 44.4 years (range = 26 -72). Eighty-five percent of the sample completed at least some high school, 63% were currently employed, and 30% were currently married. Income (household) was as follows: < \$10,000 (n=12); \$10,000-\$19,999 (n=31); \$20,000-\$39,999 (n=39); \$40,000-\$59,999 (n=17); \$60,000-\$100,000 (n=8); >\$100,000 (n=1). For statistical analyses, these categories were collapsed into two (<\$40,000, ≥ \$40,000).

To be eligible, participants had to be 25 years or older, be able to read/write English and be able to provide meaningful informed consent. To reduce sources of heterogeneity in outcome variables, women currently taking prescription medication other than hormone replacement therapy or birth control pills were excluded. Women taking over-the-counter medications were not excluded.

Participants were recruited from the clinic on scheduled clinic days by an African American female researcher (JG), as follows. The study was briefly described to a group of women in the waiting room. Interested women approached the researcher who verified eligibility criteria and obtained informed consent. Less than 10% of interested women declined participation and consistent with our IRB regulations we have no information on these women. After agreeing to participate, all were given an appointment to meet with the researcher three to four weeks afterwards, to complete study questionnaires at a time when no clinical services were provided. None of the participants had been found to have breast abnormalities. Because volunteers were accepted into the study, and women were not individually invited to participate, refusal rates are not available.

After the first scheduled visit, participants returned twice more to the clinic, solely to complete study assessments, and visits were approximately one month apart. We conducted multiple assessments of critical outcome variables to increase reliability over "one shot" assessments that are more common in the literature. In addition, by aggregating across three assessments, we increased the base rate of outcome variables (e.g., colds). Measures were completed while an investigator was present, so that questions could be answered. However, participants had the option of completing the demographic questionnaire at home and returning it later. Participants were offered \$20 plus the cost of public transportation to and from each visit. Because so few ( $n=3$ ) of the women who began the study ( $n=74$ ) did not complete all assessments, it was not appropriate to analyze differences between "completers" and "non-completers" on outcome variables.

Study variables

All questionnaires were written self-report measures. A standard demographic questionnaire (50) was used to obtain information such as age, marital status, education, employment, and income.

General psychological distress in the past three weeks was assessed with the Brief Symptom Inventory (BSI), a 53-item standardized measure with strong internal consistency (51). A general distress index was calculated by obtaining the mean of all items, with higher numbers indicating greater distress. These scores were averaged across three assessments.

Lifetime smoking status was assessed with a single item from the National Health Interview Survey (52): "During your lifetime, have you smoked at least 100 cigarettes (5 packs)?" To provide an indication of recent smoking, at each study assessment, participants reported how many cigarettes they smoked: "today," "yesterday," "2 days ago," and "3 days ago". Occurrence of alcohol consumption was reported for the past month (yes/no), and recent quantity consumed was assessed, as was recent smoking. The responses to these questions were averaged across the three visits.

The women's perception of their own health was assessed at the initial visit, with a well-established single item assessment: "In general, how is your health compared to other people your age?" (53, 54). Responses were given with a 5-point Likert scale with "1" representing "Excellent" and "5" representing "Poor". To assess lifetime history of disease, participants reported the occurrence of ever having been diagnosed by a doctor with a system by system checklist of diseases (e.g., gastrointestinal, immunological, infectious, endocrine). The total sum of these lifetime illnesses was used as another index of physical health. During each study assessment participants reported the occurrence and frequency of colds in the past three weeks.



These responses were averaged over the three assessments, thus covering a nine week interval. Self-reported cold numbers have been found to be valid in a previous study that confirmed such reports with physical exams (55).

Experiences with racism were assessed with the Schedule of Racist Events (SRE) (34, 43) at the first study assessment. The scale is an 18-item self-report inventory that measures the frequency with which African Americans have experienced racist events (on a 6-point scale ranging from "Never" to "Almost all of the time"). Item content is listed in Table 1. For each item, ratings for the past year and lifetime are requested, as well as the degree of stress associated with each experience. The mean score for responses in each of the three facets are computed.

#### Statistical analyses

To investigate group differences (e.g., past year racism in smokers vs. non-smokers), analysis of variance (SAS statistical package) was used. To investigate the strength of the association between racism and health outcomes, Pearson-product moment correlations were computed. To determine whether discovered relationships could be explained by other variables, SAS general linear model (GLM) was used as a regression model. Thus, if a significant relationship was discerned between experienced racism and a health outcome, the GLM was used to determine if this relationship persisted after controlling for other relevant variables.

### Results

#### Descriptives

The mean for past year racism (PYR) was 1.71 (SD= .65), lifetime racism (LTR) was 2.36 (SD= .98) and appraisal of stress (AOS) was 2.79 (SD=1.32). Given that a score of "1" indicates "Never" experiencing the racist event listed in the item, and "2" indicates "Once in a

while," there was not a high level of racism experienced in the sample. Bivariate correlational analyses revealed no significant relationships between any demographic variables (i.e., age, marital status, education, income, or employment status) and any facet of experienced racism. Income was positively related to lifetime history of disease,  $r = .23$ ,  $p < .01$ , and cold frequency,  $r = -.25$ ,  $p < .05$ . Income was not significantly related to drinking or smoking.

Table 1 shows the item-by-item frequency of past year and lifetime experienced racism in the sample. As can be seen, most participants had experienced some racism in their lives, including more severe events such as having to take drastic steps regarding the racist event (e.g., lawsuit).

#### Health outcomes and racism

Table 2 shows the bivariate correlations, significance levels and  $r^2$  values for the three facets of experienced racism and each health outcome. As can be seen, experienced racism was positively correlated with overall psychological distress.

None of the facets of experienced racism were related to ever being a lifetime smoker. However, for individuals who were smokers ( $n=34$ ), PYR was related to how many cigarettes were smoked. Distress did not account for the relationship between PYR and smoking, as adding it to the model did not eliminate the significance of the relationship,  $F(2, 31) = 5.03$ ,  $p < .05$ , as shown in Table 3.

PYR was related to whether or not women drank in the past month, but this was an inverse relationship; non-drinkers experienced more racism than drinkers,  $F(1, 69) = 5.44$ ,  $p < .05$ . Again, however, among drinkers ( $n=33$ ), PYR was positively related to how many drinks were consumed, as shown in Table 2. The relationship between PYR and quantity of drinks did not

appear to be accounted for by distress; adding distress to the model did not eliminate the significance of the relationship,  $F(2, 30) = 5.78, p < .05$ , as shown in Table 3.

With regard to perceived health, women who had experienced more LTR rated their overall health as poorer, as shown in Table 2. When distress, drinking and smoking were added to the model, the relationship between LTR and perceived health was no longer significant. Drinking and smoking did not account for the relationship, as racism remained significant with these variables. However, distress appeared to be a mediator, as including it by itself in the model eliminated the significance of the relationship,  $F(2, 67) = 2.12, p = .15$ , as shown in Table 3.

LTR was positively related to lifetime history of disease, as shown in Table 2. Including distress, smoking and drinking in the model did not affect this relationship,  $F(4, 65) = 4.88, p < .05$ . For the common cold, only PYR was positively related to having a cold in the nine weeks assessed,  $F(1, 68) = 5.33, p < .05$ . However, among women who had colds ( $n=47$ ), both PYR and LTR were significantly related to the *number* of colds women experienced (see Table 2). The relationship between racism and cold frequency was not explained by distress, drinking or smoking. After adding these variables to the model, PYR still remained significant,  $F(4, 42) = 4.83, p < .05$ , as did LTR,  $F(4, 42) = 5.09, p < .05$ , as shown in Table 3.

### Discussion

The results of the present study supported the hypotheses that individuals who reported having experienced racism would have higher levels of psychological distress, negative health behaviors and physical health problems. More specifically, greater experienced racism (higher scores on the Schedule of Racist Events) was associated with higher distress, greater alcohol and cigarette consumption, more common colds, and more lifetime illnesses. The study's findings

are concordant with those in the literature, but also introduce new findings with drinking behavior, and, to the best of our knowledge, provide the first data to show a relationship between experienced racism and physical health outcomes outside of the cardiovascular system.

It is important to note that experienced racism did not vary significantly by a variety of demographic variables including age, income or education, evidence of the widespread nature of racism. It is also noteworthy that the women in this sample did not report extreme levels of experienced racism. Some researchers contend that recognition of discrimination may adversely affect self-esteem and perceptions of control, and as a result, these experiences may be denied or minimized (37). The vast majority of the present participants reported having experienced some form of racism during their lives, including having to take drastic steps such as lawsuits to remedy the situation. It is possible that these reports even underestimate the actual level of experienced racism. Given that the relationships were found with relatively low levels of racism, African Americans who experience more severe levels may be at even greater risk for poor health outcomes.

Experiences with racist events accounted for a fair amount of variance in health outcomes ( $r^2$  values). It is not surprising that only 5% of the variance in lifetime history of disease was attributable to lifetime racism, given the important role of other factors such as lifestyle (e.g., diet, exercise) genetics, immune function, physical environment, etc. However, that even 5% of the variance is accounted for by lifetime experienced racism highlights the effect racism has on African Americans. Psychological distress, quantity of cigarettes and alcohol consumed, and frequency of common colds showed higher  $r^2$  values. Again, a range of 14%-17% is not trivial when we consider the number of other variables that may be related to these outcomes. In

addition, that racism experienced over a *lifetime* accounted for 16% of the variance in distress experienced in the past *two weeks* is notable.

### Racism and health behaviors

In this study, experienced racism was not related to whether or not women smoked. However, it did predict whether women were drinkers, with those who experienced *less* racism being more likely to drink. This was an unexpected finding. Based on their empirical data, Jackson et al. (32) argue that individuals who perceive whites as wanting to keep blacks down may be more vigilant when it comes to their own physical health; they are more likely to recognize the importance of looking out for themselves. This is a possible explanation for the inverse relationship found in this study. Many African Americans are aware of the disparities in alcohol sales among African American and European American neighborhoods (56), as well as the targeted marketing of malt liquors and other alcoholic beverages (57). Thus, those who have more individual experience with racist events might be more vigilant in avoiding substances that are readily connected to racism.

The more consistent finding was that women who engaged in either drinking or smoking did so with increased frequency as a function of experienced racism. Interestingly, this relationship was not mediated by distress levels assessed here. It is possible that distress would act as a mediator if measured by an instrument other than the Brief Symptom Inventory. For example, race-related stress (58) may be more predictive for African Americans than general, global distress.

### Racism and physical health

Experienced racism was related to lifetime history of disease and recent experience of common colds. The mechanisms behind this relationship between racism and physical illness

bear further exploration. In this study, neither the higher lifetime history of disease, nor the higher frequency of common colds associated with experienced racism were mediated by drinking, smoking or general distress. It may be that experiences of racism lead to compromised immune functioning. Given that racism represents a source of substantial stress, exposures to racist events may have deleterious effects through multiple pathways (25). Thus, the role of experienced racism as a contributor to health disparities should be investigated. Institutional racism results in inequalities in living conditions and access to health care (59), which in turn results in poorer health status for African Americans. However, the present data suggest that individual experiences of racism may be a factor in the disproportionate burden of illness in the African American community. Moreover, conscious awareness of racism as a stressor may not be necessary to result in physiological stress responses. In our study, appraisal of stress due to racism was not related to health outcomes; rather, the frequency of racist events alone predicted negative health outcomes.

#### Limitations of the present study and directions for future research

First, because this study is cross-sectional in design, causality between experienced racism and health outcomes cannot be established. Second, we used only self-reports for study variables (e.g., instead of endocrine measures of stress). However, as previously noted, self-reports of colds have been found to be reliable (55). Third, the sample size was relatively small, and was comprised of urban African American women recruited from a cancer screening clinic, which limits generalizability. Finally, although we found no support for the possibility that relationships between experienced racism and health outcomes were due to confounding demographic variables, we cannot rule out the possibility that other demographic indices (e.g., insurance status, generational wealth) would have yielded different results.

African American men, as well as the larger community of individuals of African descent should be the subject of future research. Much of the research on racism has been conducted with African Americans, as opposed to individuals from the Caribbean or the African continent who reside in the United States. Clearly, it is unlikely that other groups in the Diaspora are immune to the effects of racism, and there may be a different picture regarding health consequences. For example, in the Caribbean, race is not often viewed as a deterrent to political or economic empowerment, and racism may not be experienced as much of a reality (60). Thus individuals from the Caribbean may not recognize racist behaviors as readily as African-Americans, as they may not have been sensitized to such events in the same way. If this is true, perhaps the same health outcomes would not emerge.

Future research should examine the effects of the more pervasive, "invisible" level of racism. Our study focused on immediate, individual-level racism: discrete experiences such as being called a racist name, or being discriminated against by service workers. Discrimination is not simply random acts of unfair treatment, but a socially structured and sanctioned phenomenon, justified by ideology (61). This deeper level of racism, which structures the everyday life of American society, has direct bearing on quality of life issues such as nutrition, clothing, shelter, medical care, safety and education and is a source of substantial stress (62). In addition, "vicariously-experienced" racism such as police brutality in the community is also likely to affect the emotional and physical health of African Americans. Indeed, some researchers have argued that the belief that one is living in a discriminatory society may itself be detrimental to health (39).

Future research should also consider the variables that may act as mediators or moderators of the relationship between racism and health. As previously discussed, with the

exception of perceived health, the relationships found in the present study were largely unaccounted for by other variables (e.g., general distress, smoking). While income was related to lifetime history of disease and cold frequency, this variable could not mediate the relationship between racism and these outcomes, as it was not significantly related to the predictor variable, racism. A mediating variable must be significantly related to both the predictor and outcome variables (63). It is possible that variables that were not assessed in this study, such as physiological reactivity to acute stressors (5, 64), or positive health behaviors, such as exercise or diet may play a role. Other variables that are likely candidates might be cultural identity and internalized racism. Internalized racism has been defined as the acceptance of negative messages about ability and intrinsic worth: "... it is characterized by their not believing in others who look like them, and not believing in themselves. It involves accepting limitations to one's own full humanity ..." (65). African Americans who think poorly about themselves may be more likely to engage in negative health behaviors, having less belief in their intrinsic worth. It has been suggested that engaging in positive health behaviors is impeded not only by cultural oppression, but also by internalization of those ideologies (66). Indeed, there is some evidence that internalized racism leads to negative health outcomes (67).

Some data suggests that a non-Africentric orientation can be detrimental (68, 69) and other studies show that an Africentric orientation can be protective against negative health outcomes (70) and is positively related to health-promoting behaviors (71). An individual's racial identity (72) or cultural worldview may be a moderating variable between experienced racism and health outcomes and should be examined in future studies. For example, perhaps individuals who are more inclined to expect racism develop a cognitive schema to deal with the stressor, whereas those who are surprised by incidents of racism suffer negative health outcomes.



As research begins to determine the mechanisms involved in negative health outcomes, interventions can begin to be formulated. Ultimately, our goal may not be to eradicate racism, but to neutralize its negative effects on health.

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Table 1

## Percentage of women who experienced racism in the past year and in their lifetime

<u>Type of racism</u>	<u>Lifetime</u>	<u>Past Year</u>
Treated unfairly by neighbors	30	18
Made fun of, picked on, pushed, shoved, or hit	36	12
Forced to take drastic steps (filing lawsuit, moving away)	37	18
Treated unfairly by people that you thought were your friends	38	27
Accused or suspected of doing something wrong (stealing, cheating)	46	27
Treated unfairly by employers, bosses, supervisors	47	34
Gotten into an argument or fight about something racist	54	17
Called a racist name	55	15
Treated unfairly by co-workers, fellow students, colleagues	61	27
Treated unfairly by teachers and professors	62	22
People misunderstood your intentions and motives	63	47
Treated unfairly by people in helping jobs (doctors, case workers)	66	34
Wanted to tell someone off for being racist but didn't say anything	66	49
How different would your life be now if you HAD NOT been treated	68	49
Treated unfairly by institutions (schools, police, courts)	70	39
Been really angry about something racist	81	50
Treated unfairly by people in service jobs (store clerks, waiters)	83	69
Treated unfairly by strangers	84	67

Note: Percentages reflect proportion of women who endorsed item (at any degree), as opposed to endorsing "Never" or "Not at all". Item content is abbreviated for space.

Table 2. Bivariate correlations between experienced racism and health outcomes

Outcome Variable	Past Year Racism		Lifetime Racism		Appraisal of Stress	
	Bivariate correlation	p value	Bivariate correlation	p value	Bivariate correlation	p value
Psychological Distress $r^2$	.31 .09	<.01	.40 .16	<.001	.32 .10	<.01
Quantity of cigarettes $r^2$	.37 .14	<.05	.13 N/A	.46	-.005 N/A	.97
Quantity of alcoholic beverages $r^2$	.40 .16	<.05	.23 N/A	.20	.11 N/A	.55
Perceived health $r^2$	.19 N/A	.12	.27 .07	<.05	.01 N/A	.95
Lifetime history of disease $r^2$	.03 N/A	.79	.23 .05	<.05	.03 N/A	.79
Common cold frequency $r^2$	.38 .14	<.01	.41 .17	<.01	.25 N/A	.08

Note: Relations to quantity of cigarettes and alcoholic beverages, and frequency of colds is reported for those individuals who smoked, drank, or had a cold during the study. Means were as follows: quantity of cigarettes= 63.0; alcoholic beverages=2.67; colds=1.66.

$r^2$  was calculated only for significant correlations. N/A, not applicable because correlations were not significant.

Table 3. Results of multivariate analyses between racism and health outcomes

<u>Outcome Variable</u>	<u>Source</u>	<u>DF</u>	<u>Type III SS</u>	<u>Mean Square</u>	<u>F value</u>	<u>Pr &gt; F</u>
Quantity of cigarettes	Distress	1	195.67	195.67	0.07	.79
	<b>PYR</b>	<b>1</b>	<b>14319.01</b>	<b>14319.01</b>	<b>5.03</b>	<b>.03</b>
Quantity of alcoholic beverages	Distress	1	.652	.652	0.05	.82
	<b>PYR</b>	<b>1</b>	<b>71.45</b>	<b>71.45</b>	<b>5.78</b>	<b>.02</b>
Perceived health	Distress	1	2.32	2.32	3.07	.08
	Quant. alcohol.	1	.803	.803	1.06	.31
	Quant. cig.	1	2.47	2.47	3.26	.08
	LTR	1	1.38	1.38	1.83	.18
Cold frequency	Distress	1	.800	.800	1.15	.29
	Quant alcohol.	1	.174	.174	0.25	.62
	Quant cig.	1	1.16	1.16	1.67	.20
	<b>PYR</b>	<b>1</b>	<b>2.87</b>	<b>2.87</b>	<b>4.13</b>	<b>.05</b>

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Acculturation and its Relationship to Smoking and Breast Self-Examination  
Frequency in African American Women

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### Abstract

The concept of acculturation has been used to understand differences in health behaviors between and within a variety of racial and ethnic immigrant groups. Few studies, however, have examined the potential impact of acculturation on health behaviors among African Americans. The present study had two goals: 1) to reconfirm relations between acculturation and cigarette smoking; 2) to investigate the impact of acculturation on another type of health behavior, cancer screening and specifically breast self-examination (BSE). African American women (N=66) attending an inner-city cancer- screening clinic completed study questionnaires. Results reconfirmed psychometric properties of the African American Acculturation Scale (AAAS) replicated the negative association between acculturation and smoking status; and found relations between African-American media preferences and women's adherence to BSE frequency guidelines. Findings from this study raise the possibility that specific aspects of acculturation may better explain specific health behaviors.

**Key Words:** African American, Acculturation, Breast Self Exam, Smoking



Acculturation refers to the process in which an individual adopts or adheres to attitudes, beliefs, practices, or behaviors congruent with that of the dominant culture (Berry, 1980).

Acculturation has been conceptualized as a confluence of traditional rituals and practices, food and activity preferences, ethnic composition of one's interpersonal relationships, values, perceived self-identity, and immigration status variables (e.g., place of birth, generational status in U.S., length of residency). Several measures have been developed to assess acculturation in populations such as Asian Americans (Suinn, Richard-Figueroa, Lew, & Vigil, 1987), Latino Americans (Marin, Sabogal, Marin, & Otero-Sabogal, 1980), and Native Americans (Hoffman, Dana, & Bolton, 1985).

For African American populations, however, acculturation has received little research attention. According to Landrine and Klonoff (1994), the identification of African Americans as a racial group, first, and an ethnic or cultural group, second, may explain the relative delay in exploring acculturation in this population. To date, only two scales have been developed to measure acculturation within the African American population (Landrine & Klonoff, 1994; Klonoff & Landrine, 1999; Snowden & Hines, 1999). Landrine and Klonoff's (1994) scale, African American Acculturation Scale (AAAS) revised in 1999 (Klonoff & Landrine, 1999) assesses several dimensions of African American culture theoretically derived to reflect the degree of connection an individual has to African American culture as opposed to the dominant culture (i.e., White American culture). Importantly, scores on the separate subscales of the AAAS have not been found to be associated with income, social class, or level of education (Landrine & Klonoff, 1994). This lack of confounding with other demographic variables suggests

its potential to explore cultural constructs as they relate to other behaviors, performance, or functioning.

In other cultural groups, acculturation has been examined increasingly as one of the factors accounting for variation in health behaviors. For example, acculturation has been found to be positively associated with ever having had a Pap test among young Asian-American women (Tang, Solomon, Yeh, Worden, 1999), having mammograms and clinical breast exams among Hispanics (O'Malley, Kamer, Johnson, & Mandelblatt, 1999), illicit drug use among Mexican men and women (Vega, Alderete, Kolody, & Aguilar-Gaxiola, 1998) and greater alcohol consumption among Mexican American women (Alaniz, Treno, & Saltz, 1999). Among Korean Americans, high acculturation is related to higher body weight and lower physical activity (Lee, Sobal, & Frongillo, 2000). In addition, smoking behavior has been linked to acculturation. Chen, Unger, Cruz, and Johnson (1999) found greater smoking behavior and earlier onset of smoking among more highly acculturated Asian American youth, a relationship also documented in other Asian and Latino populations of varied ages (Ebin, et. al, 2001; Lee, Sobal & Frongillo, 2000; and Unger et. al, 2000).

Few studies have examined the relationship of acculturation and health behaviors among African-Americans (Landrine & Klonoff, 1994; Klonoff & Landrine, 1999; Brook, Whiteman, Balka, Win, & Gursen, 1997). Landrine and Klonoff (1996) used the AAAS to examine the role of acculturation in cigarette smoking, and found that African Americans who scored as less acculturated were more likely to be smokers. Klonoff and Landrine (1999) later replicated this finding in a community sample. Here, the researchers found a significant association between the total acculturation score and smoking status, with less acculturated African Americans being

more likely to smoke. The role of acculturation in secondary prevention (e.g., breast cancer screening) has not previously been investigated.

Although breast self-exam (BSE) has not been proven unequivocally to be effective in detecting breast cancer or reducing mortality related to the disease, it has been recommended consistently by national clinical societies (e.g. American Cancer Society, American Society of Clinical Oncology) as an important aspect of breast cancer surveillance and has been shown to detect a substantial number of breast cancers (Porter, 1999). Among economically disadvantaged groups, cost can be a barrier to participating in clinical breast cancer screening (Rimer, 1992). Given that BSE is a cost-free screening procedure that is under a woman's personal control, examining BSE behavior among African American women is particularly relevant. Existing studies on BSE among African American women have yielded inconsistent results, with some indicating African American women tend to under-perform BSE (Underwood, 1999) and others indicating African American women tend to over perform BSE (Epstein et al., 1997). While BSE under-performance is well recognized to decrease the utility of this screening modality, BSE over-performance may also decrease efficacy by reducing women's ability to detect gradual changes in the breast (Haagensen, 1952).

As an example of a self-initiated secondary prevention behavior, it is important to understand factors that may encourage or deter BSE among African American women. The aims of the present study were to re-examine the relationship of acculturation and smoking status in an urban, inner city sample of African American women, and to examine the role of acculturation in another health behavior (BSE frequency). The AAAS has been recently revised to drop 26 items (Klonoff & Landrine, 2000), based on feedback from other investigators who reported that

highly acculturated subjects may find the scale offensive, therefore, care was taken to explain the purpose of the measure to all participants. In our sample, only one woman refused to complete the measure, saying she did not see its relevance to her experience. Participants received \$20 plus the cost of round trip public transportation for the visit.

### Participants.

To be eligible, participants had to be 25 or older, able to read/write English, and able to provide meaningful informed consent. The study excluded women who had a personal history of neoplasm, or abnormal pathologic reports, or were pregnant.

### Measures.

Demographic and Medical questionnaire. A standard questionnaire (Valdimarsdottir et al., 1995) was used to obtain information on age, education, and other demographic variables. Age ranged between 26 -72 years, ( $M = 45.00$ ,  $SD = 10.70$ ). Eighty-five percent completed at least some high school. Income was trichotomized into  $< \$10,000$  (18%);  $\$10,000$ - $\$39,000$  (61%); and  $> \$39,000$  (21%). Sixty-three percent were currently employed, and 30% were currently married. Forty-five percent were smokers as indicated by their responses to a question taken from the National Health Interview Survey (Benson & Marano, 1995): "During your lifetime, have you smoked at least 100 cigarettes (5 packs)?" Smoking was unrelated to demographics in this data set.

African American Acculturation Scale (AAAS). The original AAAS measure contained 74 items (Landrine & Klonoff, 1994) assessing eight dimensions of African American culture, whereas the revised version consists of 47 items (Klonoff & Landrine (2000) assessing seven dimensions of African American culture (see Table 1). A subject's score on a sub-scale is

computed as the sum of the answers on that sub-scale, and a Total Summary Score is also computed. A higher score is thought to represent more traditionally African American views.

Assessment of breast self-examination. Two questions based on published methods assessed breast self-examination frequency. First, participants were asked: "How often do you perform breast self-examination? (1) *More than once a month*; (2) *Once a month*; (12 times a year); (3) *Every other month* (6 times a year); (4) *Four or five times a year*; (5) *Two or three times a year*; (6) *Once a year*; (7) *Never*. Under-performance was operationally defined as those women who performed BSE less than once a month. Second, over-performance in the period following their clinical examination was evaluated with the question: "In the past three weeks, how many times did you perform breast self-examination? (a) *Never* (b) *Once* (c) *2-3 times* (d) *4-5 times* (e) *Six or more times*." Over-performance was operationally defined as performing BSE more than once during the prior three weeks. As would be expected, results on the two measures of BSE frequency were significantly related ( $\chi^2 = 55.36, p < .001$ ).

## Results

### Phase 1 -

We first examined the psychometric properties and concurrent validity of the AAAS. Consistent with previously published results (Landrine & Klonoff, 1994), data from this sample ( $n=35$ ) demonstrated a wide range of scores. Also consistent with published findings (Landrine & Klonoff, 1994; Klonoff & Landrine, 1999), in this data set scores on the AAAS were not significantly related to demographic variables for either version.

We next examined concurrent validity of the original and the revised AAAS scales by following the previously published approach of the scale's developers. They argued that persons

of an ethnic group who live in an ethnic-minority neighborhood are likely to be the more traditional members of their culture (because of constant exposure to the culture), whereas those who live in predominately White or integrated neighborhoods are likely to be more acculturated (Landrine & Klonoff, 1994). Thus, we examined the scores of the answers to the question "I currently live in a Black neighborhood" and divided the subjects into two extreme groups: 1) The "Other residence" group consisted of the women in this sample who circled "This is absolutely not true of me" and 2) the "Black neighborhood residence" group who circled "This is absolutely true of me". MANOVA analyses revealed that the Black neighborhood group scored significantly higher (i.e., more traditionally African American) than the other residence group (i.e., more acculturated) across the eight original sub-scales ( $F=2.86, p < .05$ ) as well as across the seven revised sub-scales ( $F=5.96, p < .05$ ).

Next we examined the relationship between acculturation and smoking. These analyses revealed that smokers ( $n=16$ ) scored higher than non-smokers ( $n=19$ ) on the Total Summary Score for both the original ( $F=5.33, p < .05$ ) and the revised version ( $F=5.53, p < .05$ ). Subsequent analyses for the sub-scales showed significant differences between the smokers and non-smokers on the Family Practices and Interracial Attitudes sub-scales (see Table 1).

Finally, we examined the AAAS scores in relation to BSE frequency. Table 2 shows the eight sub-scales and their relationship to BSE frequency for both the original and revised version of the scale. ANOVA results revealed that the mean for BSE "Under-performers" ( $n=17$ ) differed from "Others" ( $n=18$ ) on the Preference for African American Things sub-scale, the Socialization summary score and on the Total Summary Score. Women who under-performed BSE (i.e., less than once a month), scored lower on these sub-scales (i.e., more acculturated). The

difference on the Preference sub-scale remained significant after Bonferroni correction to reduce possible Type I error associated with assessment of multiple outcomes (i.e.,  $p < .05$  divided by 9 = .005) for testing this novel hypothesis. Consistent with these results, analysis of BSE over performance indicated that "Over-Performers" ( $n=17$ ) also differed from "Others" ( $n=18$ ) on the Preference for African American Things and Socialization sub-scales, as well as on the Total Summary Score. We found that women who over-performed BSE scored significantly higher on the Preference sub-scale of the AAAS (i.e., higher scores indicate greater preference) even after Bonferroni correction. An identical pattern of significant effects was observed with the data from the revised version of the scale (see Table 2).

#### Phase 2 –

In this phase of the study, an additional 31 women completed only the Preference for African American Things sub-scale (12 items) in addition to the other study measures, to provide confirmatory data on the relationship between this sub-scale and BSE frequency. The focus on that sub-scale served to reduce participant burden, while providing additional data on the AAAS sub-scale that had the strongest significant relation to BSE frequency in Phase 1. Continuing to support results found in Phase 1 in the combined sample, women who under performed BSE in the combined sample ( $N=66$ ) scored significantly lower on the Preference for African American Things sub-scale ( $F = 6.42, p < .013$ ); the mean score for "Under-performers" ( $N=31$ ; mean 45.48, S.D. 13.82) versus "Others" ( $N=35$ ; mean 53.53, S.D. 11.98). For over-performance the pattern was not altered from that seen in Phase 1; the mean Preference scores of "Over-

Performers" (N=23; mean 56.23 S.D. 9.42) was significantly higher than for "Others" (N=43; mean 46.28, S.D. 14.01) ( $F = 9.29, p < .003$ ).

Given the findings relating Preference scores and BSE frequency, it was of interest to examine the individual items on that sub-scale as a first step in considering potential explanations for the relations (Table 3). For BSE under-performance, only questions 18 (*i.e., I read, or used to read, Essence magazine*) and 23, (*i.e., I read, or used to read, Jet magazine*) reached significance after applying Bonferoni correction as appropriate for testing a novel hypothesis. The mean score of women who under-performed BSE was significantly lower on those questions ( $F=10.72$  and  $F=10.26$ , respectively;  $p < .002$  for both questions). For BSE over-performance, only question 16 (*i.e., I listen to Black radio stations*) reached significance. The mean score of women who over- performed BSE was significantly higher on question 16 ( $F=10.58; p < .001$ ).

### Discussion

The objectives of this study were to re-confirm the psychometric properties and validity of the African American Acculturation Scale (AAAS) (Landrine & Klonoff, 1994) in an independent sample of urban, inner city African American women, to re-examine the relationship between acculturation and smoking status, and to investigate the role of acculturation in breast self-examination (BSE). We found ranges in variability for total acculturation and dimension scores that were similar to those found by scale's developers, and also found that women who lived in a African American community scored higher on the AAAS (*i.e., less acculturated*) compared to women who lived in a integrated community. Also consistent with initial reports by



the scale's developers, we did not find responses on the AAAS to be associated with income or level of education. Finally, we also replicated the relationship between acculturation and smoking status reported in previous studies by the scaling developers) (Landrine & Klonoff, 1996; Klonoff & Landrine, 1999). Consistent with those studies, we found a negative association between acculturation and smoking, with less acculturated African American women more likely to be smokers.

Interestingly, one acculturation dimension that predicted smoking status in the present study, as well as those conducted by the scale developers, was Family Structure and Practices. This dimension reflects the extent to which one's immediate and extended family adheres to practices, customs, and values (e.g., informal adoption) specific to African American culture (Landrine & Klonoff, 1994). In this study, and in the studies by Landrine and Klonoff, the opposite was found to be true: smokers were more likely to score higher. The items contained in this sub-scale assess participation in traditional African American family practices (e.g., information adoption or "child-keeping,"). One hypothesis that may explain these findings is that individuals scoring higher on this sub-scale may be more likely to be exposed to extended family members who smoke, and therefore more likely to adopt the behavior themselves. The other acculturation dimension related to smoking was Interracial Attitudes. One hypothesis that may explain these findings is that individuals who perceive greater racism may be more likely to smoke than those who do not (Landrine & Klonoff, 1996; Guthrie, Young, Williams, Boyd & Knitner, 2002).

The final aim of this study was to explore the role of acculturation in BSE under-performance and over-performance. Breast self-exam is related to earlier pathological stage of

cancer diagnosis and symptom presentation, and continues to be recommended strongly as an important breast cancer screening modality by the American Cancer Society (ACS, 2000) and the American Society of Clinical Oncology (Smith et al., 1999), respectively. With regard to rates of BSE performance, fifty-one percent of the women in this study reported performing BSE at least once a month. This rate is consistent with the rate (49.7%) reported in a random sample of low income, African American women ages 40 and over living in a Florida city (Mickey, Durski, Worden, & Danigelis, 1995) and also falls into the range (41 % to 67%) reported for other populations of women 50 and older in the U.S. (NCI Breast Cancer Screening Consortium, 1990).

While under-performing BSE has obvious implications for the utility of this screening modality, less appreciated are the potential drawbacks to over-performing BSE. It has long been recognized that over-performing BSE may decrease a woman's ability to detect gradual changes in the breast as well as induce cancer anxiety (Haagensen, 1952). Excessive BSE performance may also be associated with increased numbers of false positive findings, which also may result in increased anxiety (Lerman, Kash, & Stefanek, 1994; Haefner, Becker, & Janz, 1989). Women may also use their over-reliance on BSE as a screening modality as a reason for opting out of, or not adhering to, other screening modalities such as mammography (Epstein & Lerman, 1997). Both under- and over-performance of BSE may then lead to diminished utility of this screening modality.

Results of the present study revealed significant associations between acculturation and BSE frequency. BSE under-performers were more acculturated, and BSE over-performers were less acculturated. In addition to identifying a relationship between global acculturation and BSE

frequency, we found the Preference for African American Things subscale was the single significant dimension of acculturation related to BSE. This subscale reflects the extent to which an individual has a preference for African American newspapers, periodicals, music, activities, arts, and people (Landrine & Klonoff, 1994), and is similar to other conceptualizations of acculturation (Snowden & Hines, 1994). Close inspection of this dimension with item analyses revealed that items related to Black print media were significantly associated with BSE under-performance, with under-performers being less likely to read these magazines.

BSE over-performance was significantly associated with one item: D) "I listen to Black radio stations", where over-performers were more likely to listen to these stations. Taken together, these findings highlight the importance of mass media in publicizing breast cancer as a major health concern among African American women. Turnbull (1978) found that a significant proportion of women increased their BSE performance from no performance/under performance to once a month or more as a result of the mass media surrounding Betty Ford's mastectomy. Additionally, women cited television/radio and periodicals/books as their number one and two sources of health information, respectively (Turnbull, 1978). Among Latina women, Richardson et al. (1987) also found those who reported reading or hearing about (via television) the importance of performing BSE were more likely to perform BSE more frequently. Based on these studies, it would appear that mass media is influential in breast cancer screening among ethnic minority women, as well as among women in general. That an association was suggested between exposure to African American mass media and BSE frequency among African American women in the present study is thus consistent with past research.

We do not know whether women who did not read Black magazines simply did not read periodicals at all. Collecting this information in future studies, would be important in determining an appropriate means by which to effectively reach this population through the press. This challenge is particularly important given that African American women have the highest rate of breast cancer mortality among women in the U.S (ACS, 2000). This differential impact of breast cancer may well be reflected and underscored in African American media sources as compared to the general mass media. Future research should compare breast cancer coverage between different media sources, examining both the frequency of breast cancer articles appearing in issues as well as accuracy and clarity of information presented.

These findings suggest the importance of identifying specific mechanisms that may influence the behavior of interest. Different health behaviors are likely to be associated with different cultural dimensions. For example, Tang et al. (1999) found that among Asian American women, modesty was related to BSE, but not other aspects of culture. And, the present study found the Family Structure and Practice dimension to be significantly associated with smoking status, as did Landrine and Klonoff, 1996, and Klonoff and Landrine, 1998. Future research should begin to investigate cultural thought and behaviors that are thought to represent a more traditional African worldview, such as a holistic and communal orientation, extended self identity and spirituality (e.g., see Montgomery, Fine and Myers, 1990; Oshodi, 1999; Baldwin, 1984). In addition, more politically informed values such as Africentrism (Grills & Lonshore, 1996) should be considered. Such research may thus assist us in targeting specific barriers for intervention.

Limitations to this study should be noted. Because the sample size was relatively small and women were recruited specifically from a low-income, inner city breast cancer-screening center, our results cannot be generalized to all African American women. Moreover, it is likely that the prevalence of BSE under-performance and/or over-performance may be higher among women who do not receive BSE education and training as those in our sample did. We deliberately selected women who were instructed by African American health care providers in proper BSE technique in order to hold BSE training, knowledge of BSE guidelines, and ethnic background of health care providers constant.

Taken together, our findings highlight the importance of identifying specific acculturation mechanisms that may influence health behaviors of interest. Different health behaviors may be selectively influenced by different acculturation dimensions. Clearly, the value of the concept of acculturation in clinical research depends on how it is operationalized and utilized in understanding and predicting the spectrum of health behaviors related to the risk of disease. By identifying specific acculturation components that facilitate or deter health behaviors, we may be better able to implement interventions to improve health status among different ethnic and cultural communities.

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**Table 1****AAAS Scores for Women With or Without History of Smoking**

AAAS Subscale	Number of Items	Smokers (n=16)	Non Smokers (n=19)	F	Sig.
Preferences (O)	11	54.06	46.00	2.41	.130
Preferences (R)	9	46.18	38.52	2.96	.094
Family Practices (O)	12	56.62	46.21	6.98	.012
Family Practices (R)	8	40.56	34.47	4.36	.045
Health Beliefs (O)	12	54.19	47.89	1.33	.256
Health Beliefs (R)	6	28.31	26.52	.43	.514
Socialization (O)	11	53.75	50.31	0.57	.453
Socialization (R)	6	28.87	28.15	.04	.843
Foods (O)	10	43.25	36.57	2.17	.152
Foods (R)	0	--	--	--	--
Religion (O)	6	36.88	31.95	2.58	.117
Religion (R)	6	36.88	31.95	2.58	.117
Interracial Attitudes (O)	7	33.19	24.95	4.56	.040
Interracial Attitudes (R)	7	33.19	24.95	4.56	.040
Superstitions (O)	5	25.31	20.26	3.83	.058
Superstitions (R)	5	25.31	20.26	3.83	.058
Summary Score (O)	74	361.37	307.84	5.33	.027
Summary Score (R)	47	282.56	241.42	5.53	.025

\* O = Original scale; R = Revised scale

Table 2

Women who Under Perform BSE Scored Lower than Women who Over Perform BSE

	Under Performance Assessment				Over Performance Assessment			
	Past year		F	Sig.	Past 3 weeks		F	Sig.
	Under	Others			Over	Others		
	Performers				Performers			
	(n=17)	(n=18)			(n=17)	(n=18)		
AAAS Subscale	Mean (S.D.)	Mean (S.D.)			Mean (S.D.)	Mean (S.D.)		
Preferences (O)	<b>41.41 (15.27)</b>	<b>57.50 (11.63)</b>	<b>12.38</b>	<b>.001</b>	<b>59.50 (7.64)</b>	<b>43.14 (16.26)</b>	<b>12.26</b>	<b>.001</b>
Preferences (R)	<b>35.47 (13.57)</b>	<b>48.22 (10.34)</b>	<b>9.85</b>	<b>.004</b>	<b>50.29 (6.72)</b>	<b>36.52 (14.16)</b>	<b>11.43</b>	<b>.002</b>
Family Practices (O)	48.71 (14.01)	53.11 (11.07)	1.07	.308	54.43 (11.20)	48.67 (13.20)	1.80	.189
Family Practices (R)	35.59 (11.00)	38.83 (6.56)	1.14	.294	39.14 (7.04)	36.00 (10.09)	1.02	.319
Health Beliefs (O)	47.24 (16.39)	54.11 (15.60)	1.62	.212	53.93 (16.18)	48.67 (16.15)	0.89	.352
Health Beliefs (R)	25.88 (8.28)	28.72 (7.53)	1.13	.296	28.21 (7.33)	26.76 (8.41)	0.28	.603
Socialization (O)	47.00 (13.93)	56.50 (11.08)	5.01	.032	58.43 (8.78)	47.52 (14.11)	6.61	.015
Socialization (R)	26.18 (11.38)	30.67 (9.38)	1.63	.021	32.64 (7.33)	25.71 (11.49)	3.99	.054
Foods (O)	35.65 (11.66)	43.39 (14.46)	3.02	.092	45.29 (13.66)	35.86 (12.41)	4.48	.042
Foods (R)	---	---	---	---	---	---	---	---
Religion (O)	31.29 (11.30)	36.94 (5.86)	3.51	.070	38.00 (4.15)	31.67 (10.83)	4.33	.045
Religion (R)	31.29 (11.30)	36.94 (5.86)	3.51	.070	38.00 (4.15)	31.67 (10.83)	4.33	.045
Interracial Attitudes (O)	27.41 (11.94)	29.94 (12.16)	0.39	.539	30.29 (12.48)	27.67 (11.77)	0.40	.533
Interracial Attitudes (R)	27.41 (11.94)	29.94 (12.16)	0.39	.539	30.29 (12.48)	27.67 (11.77)	0.40	.533
Superstitions (O)	20.29 (8.89)	24.72 (6.37)	2.89	.099	25.71 (6.51)	20.48 (8.21)	4.01	.054
Superstitions (R)	20.29 (8.89)	24.72 (6.38)	2.89	.099	25.71 (6.51)	20.48 (8.21)	4.01	.054
Summary Score (O)	302.82 (79.07)	360.17 (54.38)	6.31	.017	369.86 (43.51)	307.29 (77.96)	7.43	.010
Summary Score (R)	237.76 (59.81)	281.44 (40.95)	6.42	.016	289.57 (33.86)	240.67 (58.07)	8.05	.008

\*Bolded numbers indicate Bonferoni corrected significance was reached ( $p < .05$  divided by 9 = .005).

O = Original scale; R = Revised scale

Note: Re-analyses excluding women whose responses revealed long-term under performance and short-term over performance (n=4) yielded an identical pattern of results.

Table 3

Individual Items from the Preference for African American Things Subscale

	Under Performance Assessment				Over Performance Assessment			
	Past year				Past 3 weeks			
	Under Performers (n=31)	Others (n=35)			Over Performers (n=23)	Others (n=43)		
AAAS Scale: Answers range from 1-7 (Strongly disagree-agree)	Mean (S.D.)	Mean (S.D.)	F	Sig.	Mean (S.D.)	Mean (S.D.)	F	Sig.
13. I know how to play bid whist	2.53 (1.99)	3.14 (2.45)	1.21	.274	3.00 (2.41)	2.77 (2.18)	.14	.707
14. Most of my friends are Black	5.22 (1.82)	5.62 (1.73)	0.85	.361	6.13 (1.21)	5.06 (1.91)	5.76	.019
15. I feel more comfortable around Blacks than around Whites	4.25 (2.12)	4.40 (2.11)	0.07	.787	4.47 (2.12)	4.25 (2.11)	0.16	.686
16. I listen to Black radio stations	4.45 (2.17)	5.22 (1.71)	2.63	.110	<b>5.86 (1.51)</b>	<b>4.32 (1.98)</b>	<b>10.58</b>	<b>0.001*</b>
17. I try to watch all the Black shows on T.V.	3.11 (2.28)	4.00 (2.30)	2.42	.124	4.60 (2.23)	3.03 (2.20)	7.55	.007
18. I read (or used to read) Essence Magazine	<b>4.38 (2.33)</b>	<b>5.97 (1.56)</b>	<b>10.72</b>	<b>0.001*</b>	6.13 (1.32)	4.74 (2.28)	7.12	.009
19. Most of the music I listen to is by Black artists	4.09 (2.19)	5.14 (1.68)	4.78	.032	5.26 (1.54)	4.32 (2.14)	3.41	.069
20. I like Black music more than White music	4.96 (2.18)	5.08 (1.90)	0.06	.810	5.34 (1.69)	4.85 (2.17)	0.88	.352
21. The person I admire the most is Black	5.22 (1.97)	5.89 (1.68)	2.17	.145	6.40 (1.06)	5.13 (2.02)	7.79	.006
22. When I pass a Black person (a stranger) on the street, I always say hello or nod at them	3.28 (2.20)	3.70 (5.33)	0.64	.426	3.53 (2.04)	3.49 (2.19)	0.00	.949
23. I read (or used to read) Jet magazine.	<b>3.93 (2.01)</b>	<b>5.33 (1.52)</b>	<b>10.26</b>	<b>0.002*</b>	5.46 (1.52)	4.25 (1.95)	6.68	.012

\* Bolded number indicated Bonferroni corrected significance was reached ( $p < .05$  divided by 11 =  $p < .004$ )

Activity and sleep contribute to levels of anticipatory distress in breast surgery patients.

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## Abstract

A high level of anticipatory distress in women scheduled for surgery to detect/treat breast cancer makes the need for investigation of potential targets for distress reducing interventions of paramount importance. Exercise and sleep have been examined in relation to distress in this population, focusing on the post-surgery period. This study examined the contributions of physical activity and sleep to anticipatory distress levels in 124 women prior to breast surgery. Patients completed measures of distress, activity and sleep. It was expected that higher levels of activity and better sleep would be associated with lower anticipatory distress. Additionally, it was expected that the effects of physical activity on distress would be accounted for by (mediated) sleep quality. Results indicated that physical activity and sleep quality were negatively related to distress ( $p < .05$ ); however, activity effects were not mediated by sleep. These findings have implications for designing interventions to reduce anticipatory breast-surgery distress.

Index Terms: breast cancer, anticipatory distress, sleep, activity



Activity and sleep contribute to levels of anticipatory distress in breast surgery patients.

Breast cancer is one of the most commonly diagnosed cancers among women in the United States.<sup>1</sup> Women scheduled for either curative or diagnostic breast surgery, to remove suspicious or cancerous tissue, experience high degrees of anticipatory distress prior to undergoing surgical procedures.<sup>2-6</sup> With several hundred thousand women undergoing diagnostic procedures each year and over 150,000 lumpectomies and mastectomies performed annually<sup>7</sup>, research examining possible areas of intervention for reducing anticipatory distress are of paramount importance. Research studies conducted in the exercise and sleep realms suggest these are two possible factors linked to distress that could serve as possible intervention foci. While both exercise and sleep have been studied in breast cancer patients in the post-surgery period, information regarding their effects prior to surgery is lacking. The literature on distress and exercise, distress and sleep and the exercise-sleep connection are outlined below, along with a discussion of the research in these areas with breast cancer populations.

Distress and Exercise

Exercise is one potential intervention focus that could result in reduction of anticipatory distress. The relationships between exercise and psychological factors including distress have been studied extensively with over 100 published reviews in this area.<sup>8-10</sup> Due to variability in populations and study methods, drawing definitive conclusions can be difficult. However, based on meta-analyses examining exercise intervention effects on distress (e.g., depression<sup>11-13</sup> and anxiety<sup>14</sup>), it appears that exercise, whether acute or long term, has the strong potential for alleviating distress.

The effects of exercise on distress prior to surgical procedures, in particular breast surgery, are as yet not clearly defined.

### Distress and Sleep

Sleep may be another intervention domain to target, especially since disturbed sleep can negatively impact distress levels. Poor sleep quality has been associated with distress in a variety of healthy female populations.<sup>15-18</sup> Rate of poor sleep and distress levels are likely to be higher in non-healthy women. For example, a study by Shaver<sup>19</sup> and associates compared women with fibromyalgia to a healthy comparison subjects and found that the healthy women reported better sleep quality as well as less distress. As with the exercise literature, the sleep literature has not examined the effects of sleep on distress levels prior to surgery to our knowledge.

### Exercise and Sleep

It seems intuitive that exercise and sleep would be positively related; however, the relationship between exercise and sleep has been debated for several years. An early extensive review by Horne<sup>20</sup> discussed methodological problems in the exercise-sleep literature that make many conclusions tenuous. First, studies examining the effects of regular exercise on sleep were lacking in the literature. Second, potentially beneficial subjective measures of sleep quality and quantity were not frequently utilized. Many of these problems still exist in the literature today.

Despite these debates, accumulating evidence suggests a positive connection between exercise and sleep. Baekeland<sup>21</sup> reported negative effects on sleep in fit subjects who were prohibited from exercising. Conversely, higher levels of fitness are associated with better sleep.<sup>22-24</sup> Results from large scale studies support the benefits of exercise on

sleep.<sup>25-31</sup> Additionally, a meta-analysis revealed that even acute exercise may have some benefits on sleep.<sup>32</sup> Furthermore, studies have found beneficial effects of exercise on sleep in people with sleep difficulties.<sup>33-36</sup>

### Exercise, Sleep and Breast Cancer

Both exercise and sleep are areas that have been explored in breast cancer populations. A small number of studies examined the positive effects of exercise on symptoms (both physical and/or psychological) in breast cancer patients.<sup>37-45</sup> While two-thirds of these studies examined distress in addition to physical symptoms such as fatigue, none have studied the role of exercise in reducing distress *prior* to surgery. Instead, all of these studies focused on the effects of exercise post-treatment (on average one year post-surgery/treatment). The study of sleep in cancer patients has focused on the development of sleep disorders during the post-treatment period. This focus is surprising as it has been reported that 48% of insomnia cases in cancer patients occur around the time of diagnosis; with distress being a significant contributor.<sup>46</sup> In general, studies have yet to examine how sleep prior to surgery may influence anticipatory distress levels.

In summary, previous studies suggest the likely relationship between exercise, sleep and distress. Therefore, it appears that exploring the effects of exercise and sleep on anticipatory distress in women scheduled for breast surgery could potentially lead to the development of new or enhanced interventions to reduce pre-surgical distress.

We propose the following three hypotheses 1) Women with higher levels of physical activity prior to surgery will have lower distress levels; 2) Better sleep will be associated with lower levels of distress; and, 3) The effects of physical activity on

distress prior to surgery will be accounted for (mediated) by sleep quality. These hypotheses will be tested in a sample of breast cancer surgery patients where heightened levels of distress prior to surgery have been demonstrated in the literature.

## **Method**

### **Participants**

The sample consisted of 124 females undergoing excisional breast biopsy or lumpectomy. From the surgical perspective, there is little difference between these procedures.<sup>47</sup> Mastectomy patients were excluded as their surgical and anesthesia procedures are markedly different. Participants, referred by their breast surgeon, were recruited following surgical consultation. All participants provided informed consent according to the guidelines of the Mount Sinai School of Medicine Institutional Review Board. In order to participate, patients had to be English speakers, over age 18 and not in psychiatric treatment for mental illness.

Age ranged from 19 to 77 years (mean age = 48.3, SD = 12.7). Seventy three point nine percent of the sample described themselves as white, 8.1% as African American, and 12.6% Hispanic. Fifty-three percent of the sample was married and 42.3% had a standard college education. Ninety six participants underwent excisional biopsies, while 28 had lumpectomies.

### **Measures and Procedures**

In the clinic waiting area, on the day of surgery, participants completed a questionnaire assessing activity, sleep and distress. The outcome variable, distress, was measured with the Profile of Mood States-Short Version (SV-POMS). The SV-POMS provides an overall mood score for the past week plus six subscale scores, and is a

shortened version<sup>48</sup> of the original POMS.<sup>49</sup> This shortened version, while less burdensome has been demonstrated to be reliable with breast cancer patients.<sup>48</sup>

In consideration of patient burden, brief measures were used to assess the predictors. Two items were used to assess sleep and one to assess activity. The first sleep question was extracted from the Functional Assessment of Cancer Therapy - Fatigue (FACT-F, version 4), a reliable and valid measure of quality of life in cancer patients with a focus on fatigue.<sup>50</sup> This question measuring sleep quality for the past week, reads as follows: "I am sleeping well," and is rated on a 0 to 4 scale where 0 indicates "not at all" to 4 indicating "very much". A similar sleep quality measure was used successfully by Moore and colleagues.<sup>51</sup> Even though sleep quality may relate better to measures of distress than sleep quantity,<sup>52</sup> the sleep deprivation literature indicates that even one night of sleep loss can have significant negative effects on mood.<sup>53</sup> Therefore, in addition to sleep quality, we decided to also gather information on the number of hours of sleep on the night before surgery to determine whether the previous night's sleep quantity affected distress.

The activity question of interest, developed for this study, asks: "In the past week, how many times did you engage in an activity long enough to work up a sweat, get the heart thumping, or get out of breath?" The purpose of this item was to capture all forms of strenuous physical activity, not only those identified specifically as "exercise". Use of such self-report approaches to measure physical activity has been found to be both valid and reliable,<sup>54</sup> while limiting additional patient burden.

The following three hypotheses were tested: 1) Women with higher levels of physical activity will have lower distress levels prior to surgery; 2) Better quality sleep

will be associated with lower levels of distress prior to surgery; and, 3) Sleep quality will account for the relation between (mediate) activity and anticipatory distress.

### Results

Neither demographic variables, body mass index (BMI) nor type of surgery (excisional breast biopsy vs. lumpectomy) contributed to distress ( $p's > .10$ ), and therefore were dropped from further analyses.

Due to lack of normality for the activity item distribution (skewness = 1.54; kurtosis=5.79), the sample was divided into two groups reflecting regularity of activity; a no/low activity group (those who engaged in activity 0-1 time over the week before surgery) and a high activity group (those who engaged in activity 2 or more times in the week before surgery).

(Insert Figure 1 about here)

Patients in the high activity group had significantly greater distress [ $t(122) = 1.93$ ;  $p=.05$ ] compared to the no/low activity group (see Figure 1). Predicted values (based on the regression equation) of SV-POMS by sleep quality scores are displayed in Figure 2. As presented in Figure 2, SV-POMS scores got progressively lower as sleep quality ratings got higher, indicating better sleep quality.

(Insert Figure 2 about here)

Both bivariate and multivariate correlations between the predictors and distress prior to surgery are presented in Figure 3.

(Insert Figure 3 about here)

To establish sleep as a mediator of the effects of activity on distress, three regression analyses were performed according to published criteria.<sup>55</sup> First, we examined

the correlation between the hypothesized mediator (sleep) and the independent variable (activity). Although sleep quality over the past week was of primary interest, as previously discussed, we also included sleep quantity (last night) in the analysis to control for the influence of this factor. Results indicated that activity was significantly correlated with sleep quantity ( $p = .01$ ), but not sleep quality ( $p > .10$ ). Therefore, data were consistent with the possibility that sleep quantity, but not sleep quality, accounted for the effects of activity on anticipatory distress according to Criterion 1. To test Criterion 2, we examined the correlation between the dependent variable (distress, as measure by SV-POMS) and the independent variable (activity). The correlation between activity and distress was significant ( $p = .05$ ) in bivariate analyses. To examine Criterion 3, we conducted simultaneous regression analyses with activity and sleep serving as predictor variables and the outcome variable being patients' distress prior to surgery (see Figure 1). Activity [ $F(1,120) = 4.90$ ;  $p = .03$ ] and sleep quality [ $F(1,120) = 29.04$ ;  $p = .01$ ] each made significant unique contributions to distress level as measured by the SV-POMS, inconsistent with mediation. Examination of sleep quantity indicated that the variable did not contribute [ $F(1,120) = 1.54$ ;  $p > .20$ ] in this simultaneous regression model. Together activity and sleep quality accounted for 22% of the variance in anticipatory distress. Thus, it appears that activity and sleep quality were each independently associated with patients' anticipatory distress.

Since sleep did not serve as a mediator, it is appropriate to examine the possible synergistic effect of activity and sleep quality on distress (total SV-POMS). To address this possibility, a simultaneous regression analysis with three predictors (activity, sleep quality and the interaction of activity by sleep quality) was performed. The interaction

between activity and sleep quality was not significant [ $F(1,120) = 1.12; p > .10$ ], indicating that there was no significant difference in the effect of sleep quality on distress for those who engage in more physical activity versus those who engage in less physical activity.

As our distress measure was comprised of six validated subscales, it was of interest to determine whether sleep quality and activity contributed differentially to the specific SV-POMS subscales. Thus, we performed separate simultaneous regression analyses for each of the six SV-POMS subscales (see Table 1). Sleep quality was significantly associated ( $p < .01$ ) with all of the SV-POMS subscales except for Vigor. However, activity was only associated with fatigue and confusion ( $p < .05$ ). The interaction between sleep quality and activity was significant only for the Confusion subscale ( $p = .04$ ), indicating that those with a high level of activity and better sleep quality reported less confusion.

To control for the possibility that distress on the day of surgery could influence retrospective ratings for sleep and distress over the past week, we used a visual analogue scale (VAS) measuring level of upset on day of surgery as a covariate in our regression original model. After controlling for distress on day of surgery, activity [ $F(1,120) = 5.48; p = .02$ ] and sleep quality [ $F(1,120) = 19.85; p = .01$ ] both continued to make significant contributions to anticipatory distress level. Again, sleep quantity did not contribute in this simultaneous regression model [ $F(1,120) = 2.49; p > .10$ ].

### Comment

Hypotheses 1 and 2 were supported; Hypothesis 3 was not. Consistent with hypothesis 1, women with higher levels of physical activity had lower distress levels



prior to surgery. Additionally, better sleep was associated with lower levels of distress prior to surgery (hypothesis 2). Interestingly, sleep quantity was not significantly associated with distress. Taken together it appears that the perception of sleep quality, rather than the actual quantity of hours of sleep, contributed to anticipatory distress. Indeed, as previously discussed, sleep quality was more likely to be related to distress as compared to quantity.<sup>52</sup>

Surprisingly, sleep quality did not serve as a mediator between activity and anticipatory distress. That is, sleep did not account for the effects of activity on distress. Additionally, there was also no synergy between sleep quality and activity. We had speculated that those that both exercised more and slept better would have the least anticipatory distress. This was not the case. Each factor contributed as a main effect, but the interaction was not significant. Further SV-POMS subscale analyses revealed a broad effect of sleep quality on specific mood states. It appears that sleep quality has a widespread effect on mood with better sleep quality correlating with less distress, while activity exerts potentially more specific effects on fatigue and confusion only.

An important contribution of this study to the literature is the examination of the effects of activity and sleep on distress prior to surgery, rather than after surgery. Future studies, however, might want to examine these variables in different contexts that were beyond the scope of this current study. For example, women with breast cancer are at generally at greater risk for developing insomnia.<sup>56</sup> An examination of the influence of distress on sleep could illuminate additional areas to target in breast cancer patients facing the threat of surgery.

This study is not without its limitations. First, the current study is correlational in design and causality cannot be assumed. Nevertheless, the study documents the associations among activity, sleep quality and anticipatory distress for the first time in the breast cancer literature. A second limitation of the study is that the activity measure only captured one week of activity prior to surgery. It is quite possible that activity during the week prior to surgery might be markedly different from a "normal" week, and activity level might not be fully captured. Yet, studies have found even acute exercise influences distress,<sup>14</sup> thus activity in the week prior to surgery might be especially crucial for relieving distress. It might also be possible that fitness level, rather than activity may be influencing distress. However, examination of BMI, a relatively stable measure associated with fitness level,<sup>57-58</sup> revealed no connection between fitness and distress. Lastly, patients were recruited from one of two surgeons, thus generalizability to other surgeons must be established. However, the diversity of our sample population in both ethnicity and economic background may allow for broader application of the present findings. Additionally, the mean anticipatory distress scores from this sample are comparable to other breast treatment/surgery populations.<sup>48,59</sup>

These results suggest that activity and good sleep may act as buffers against distress associated with breast cancer surgery. Indeed, these data support the view that interventions to increase activity and improve sleep quality may help reduce anticipatory distress. As activity and sleep are also easily identified intervention targets, an empirical test of such interventions seems warranted.

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Figure 1. Mean SV-POMS score by Activity Group

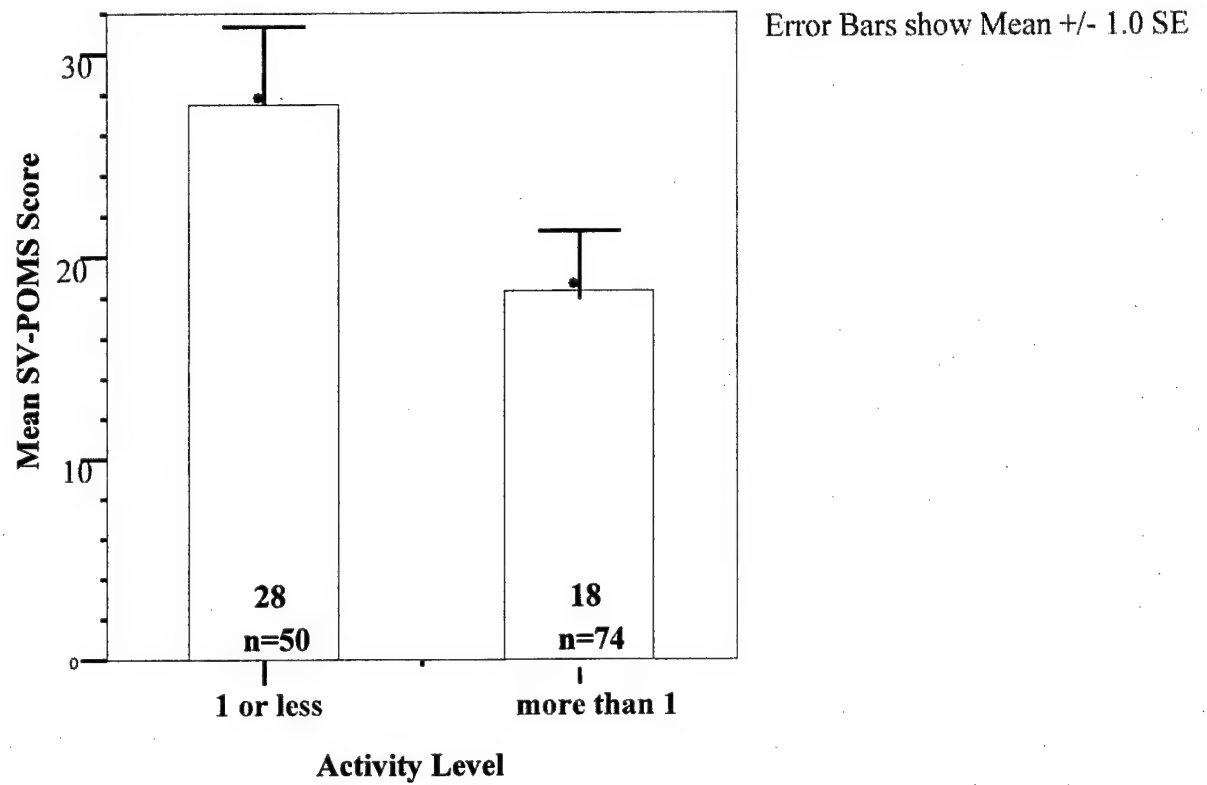


Figure 2. Predicted Values of SV-POMS by Sleep Quality

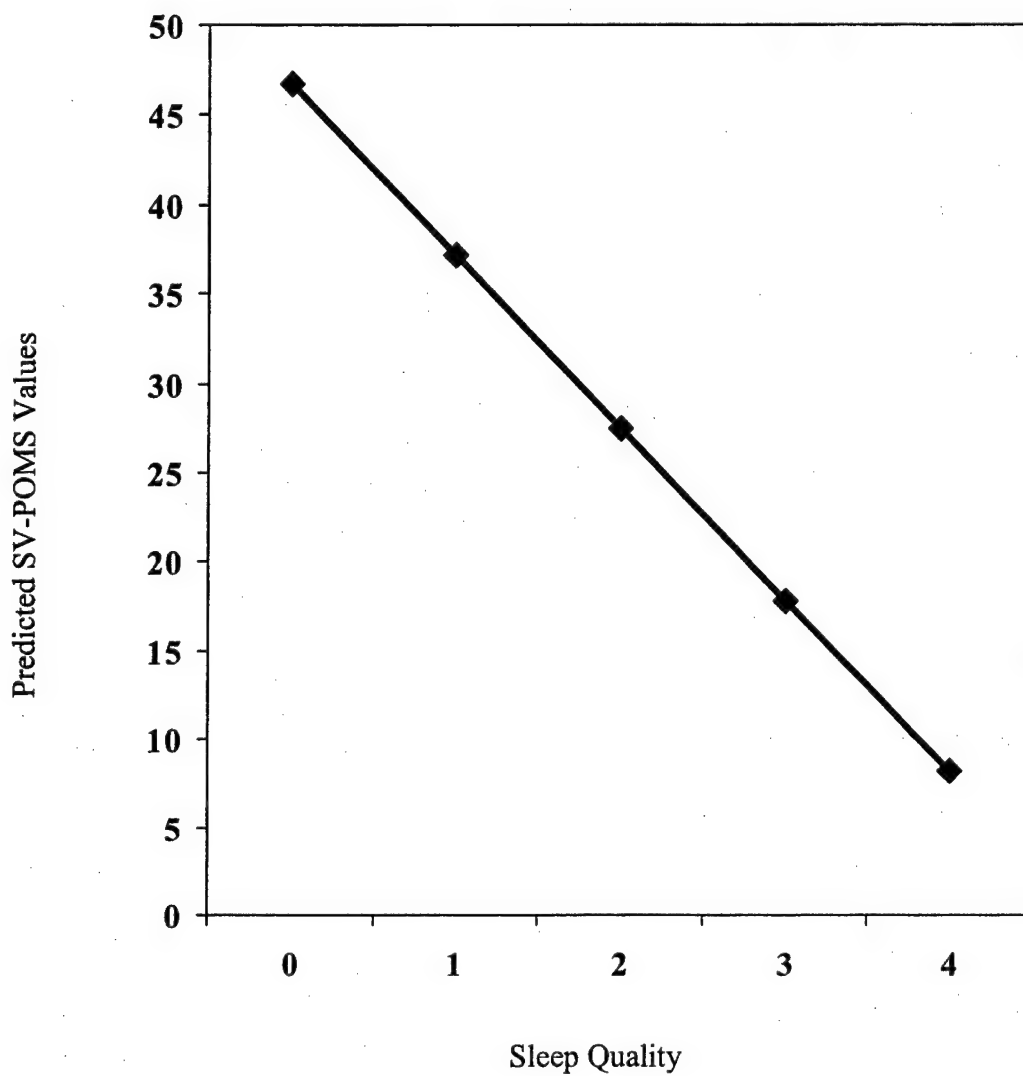
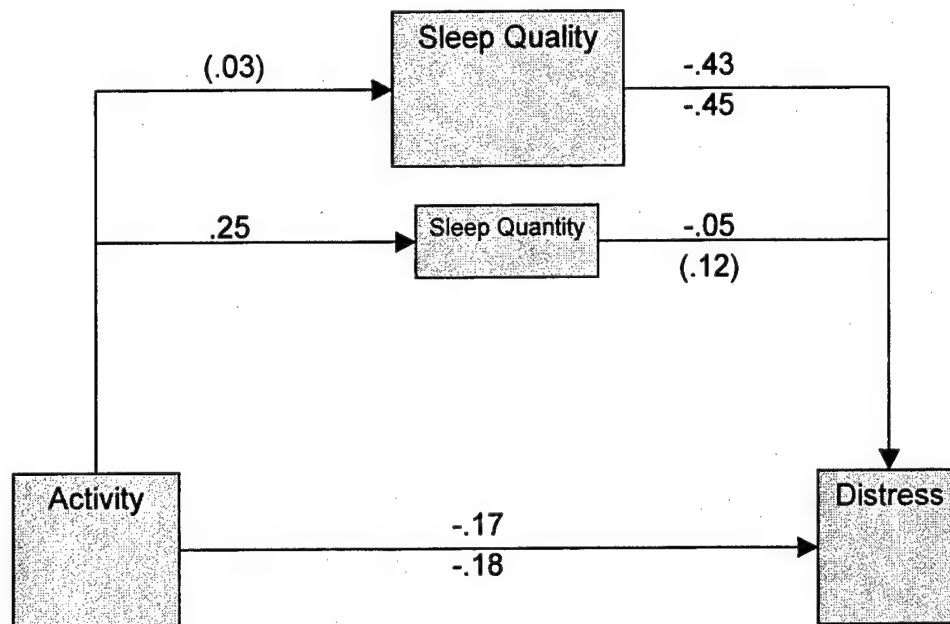


Figure 3. Correlations between Activity, Sleep and Anticipatory Distress



Note: Values above the lines represent individual bivariate regression coefficients; Values below the lines represent standardize beta coefficients with all variables entered in the regression model; Values in parentheses are non-significant ( $p > .05$ ).

Table 1. Simultaneous regression analyses of activity, sleep quality and the interaction of activity and sleep quality as potential predictors of patient distress (SV-POMS subscales).

Predictor	B	$\beta$	p
<b>SV-POMS Tension</b>			
Activity	-.78	-.06	.76
Sleep Quality	-1.93	-.36	.01
Act*Sleep Qual	-.37	-.09	.68
<b>SV-POMS Depression</b>			
Activity	-5.18	-.39	.06
Sleep Quality	-2.79	-.50	.01
Act*Sleep Qual	1.32	.31	.17
<b>SV-POMS Hostility</b>			
Activity	-3.80	-.32	.12
Sleep Quality	-2.25	-.45	.01
Act*Sleep Qual	.89	.24	.30
<b>SV-POMS Vigor</b>			
Activity	.88	.07	.74
Sleep Quality	-.14	-.03	.84
Act*Sleep Qual	-.42	-.11	.65
<b>SV-POMS Fatigue</b>			
Activity	-5.00	-.45	.02
Sleep Quality	-2.49	-.53	.01
Act*Sleep Qual	1.17	.33	.13
<b>SV-POMS Confusion</b>			
Activity	-4.54	-.52	.01
Sleep Quality	-2.18	-.59	.01
Act*Sleep Qual	1.31	.47	.04

Note: df = (1,120) in all cases.

Running Head: COLLABORATIVE CANCER SCREENING

East Harlem Partnership for Cancer Awareness (EHPCA):

collaborative cancer screening and prevention research

in an urban minority community

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### Abstract

Overall cancer incidence and mortality rates have decreased within the U.S. The burden of cancer, however, remains unequal among ethnic, gender and socioeconomic groups. African Americans have the highest age-adjusted cancer incidence and mortality rates in the U.S., and cancer is the second leading cause of death among Hispanics. Such increased risk is related to inadequate access to information regarding cancer prevention/screening and reflects multifactorial barriers. These findings present an initial report of an exploratory needs assessment conducted through a community-based, multi-site and multi-disciplinary initiative designed to increase rates of cancer screening in an inner-city neighborhood.

The breakdown of sociodemographic characteristics revealed significant differences between Hispanic sub-groups as well as African Americans, including country of birth, level of education, number of children, employment status, income, age, and site of health care. Additional differences in a comparison of recruitment sites included ethnicity, marital status, health insurance, religion, and health care access. With the exception of language, no differences were observed within clinic sites.

Significant differences between Spanish-speaking Hispanics and both African Americans and English-speaking Hispanics point to the importance of acculturation. Such differences may affect group knowledge, attitudes, beliefs and behaviors relative to cancer screening. Targeted interventions to address such variability are discussed.

## Introduction

The East Harlem Partnership for Cancer Awareness (EPHCA) is a unique interdisciplinary collaboration between an academic medical center, the Mount Sinai School of Medicine; a community hospital, Metropolitan Hospital Center; and local community health centers, Boriken Neighborhood Health Center and Settlement Health. The Partnership was formed in April 2000 to address a serious public health issue: the disproportionate rates of cancer incidence and mortality among the predominantly Hispanic and African American residents of the East Harlem, New York, community. Indeed, the incidence and stage of prostate and colorectal cancer among adults ages 45-64 living in this community are significantly higher than the average for New York City. Although the incidence rate for breast cancer among women ages 45-64 is actually lower in East Harlem than the average in New York City, women in East Harlem are diagnosed with breast cancer at later stages of the disease. Malignant neoplasms are the second leading cause of death in East Harlem after heart disease, with an age-adjusted rate of 147 per 100,000, compared to 91 per 100,000 for the rest of New York City (1).

The objective of the Partnership is to develop educational strategies to reduce barriers to screening for cancer in minority and other disadvantaged populations of East Harlem, as outlined in the Mission Statement:

The East Harlem Partnership for Cancer Awareness (EHPCA) was established to increase the rates of cancer screening among African American and Latino residents of East Harlem and other urban medically underserved communities where screening rates are low and disparities in the incidence of cancer are great. The Partnership brings together community leaders, public health professionals and researchers in cancer prevention for the Mount Sinai School of Medicine, Metropolitan Hospital Center, Boriken Neighborhood Health Center and Settlement Health. The primary goal is to increase participation in state of the art cancer screening and prevention programs.



## Background

From 1992 through 1998, overall cancer incidence and mortality rates decreased within the U.S. (2). While this decline indicates improvement, such progress is not universal. The burden of cancer remains unequal among ethnic, gender and socioeconomic groups and the reduction of incidence and mortality among all populations is a priority identified by the National Cancer Institute (3). In the U.S., the two largest ethnic minorities, African Americans and Hispanics, have sizable populations in the lower socioeconomic strata and fall into the categories of underserved and high risk populations (4).

## Ethnic Minorities and Cancer

In spite of recent improvements in both incidence and mortality, African Americans continue to have the highest age-adjusted cancer incidence and mortality rates of any population group in the U.S. (5), with late diagnosis of breast, prostate and colorectal cancers contributing to higher mortality (6).

Cancer is the second leading cause of death among Hispanics, after heart disease (7). While experiencing substantially lower incidence and mortality from all cancers combined, Hispanics have a higher burden of cancers of the stomach, liver and cervix (3). Of particular concern are indications that Hispanics have the lowest level of appropriate cancer screening behavior among major ethnic groups (8).

## Cancer Screening

As a secondary method of prevention, cancer screening promotes early diagnosis and treatment (9). In light of the difficulty in identifying the causes of cancer or in affecting behavioral change to decrease cancer incidence, cancer screening is strongly recommended by the Centers for Disease Control and Prevention (CDC) (10).

Ethnic minorities face a number of health access barriers to cancer screening, broadly categorized as: sociodemographic (8,11,12); acculturation (13,14); culture-specific beliefs and practices (8); and insufficient provision of preventive health care information (15).

#### Sociodemographic barriers

Minority group status is often associated with lower levels of education and related lower occupational status and income (16). As a result, minority group members are less likely to seek preventive care or screening tests, and are more likely to rely on emergency rooms for routine health care, the utilization of which may pose an additional barrier due to the lack of established physician-patient relationships or emphasis on preventive medicine (17). Related economic barriers to health care include: the need for child care, inadequate transportation, and loss of pay while obtaining care related to restricted hours of operation of health care facilities and limited availability of sick leave(18-20).

#### Acculturation Barriers

Acculturative barriers include traditional beliefs about the causes of disease (e.g., cancer is caused by "bad blood" or "evil spirits") (21); inaccurate self-estimates of risk (9, 22-24); and a view of cancer prevention as ineffective or nonexistent (25). Highly acculturated Hispanics have been shown to have similar cancer related knowledge and risk behaviors as non-Hispanic Whites (33), with less acculturated Hispanics exhibiting more fatalism in their attitude about cancer being "unpreventable" and "a death sentence" (34).

#### Culture-Specific Beliefs and Practices

Previous negative experiences with the health care professions; mistrust of health care providers, and belief in spirituality as an alternative to medical care are examples of culture

specific beliefs which may contribute to non-compliance with cancer screening recommendations (8).

#### Insufficient provision of cancer prevention information

There is evidence that ethnic minorities do not get the same level of preventive care information as non-minorities, and that medically underserved minorities in general have less knowledge about cancer than Whites (15).

#### Preliminary Goal

In summary, ethnic minorities experience increased risk of cancer incidence and mortality related to lack of access to information regarding cancer prevention and screening. Such lack reflects multifactorial barriers including low socioeconomic status, institutional barriers to health care and issues of acculturation. Community based interventions are a recognized approach to improving the health status of these special populations (26). Rather than impose interventions on the community, it is preferable for community-based interventions to be shaped, monitored and evaluated by the community in order to meet documented needs in an effective, culturally-appropriate way (27). With this as a guiding principle, and prior to initiation of any education or intervention, the first aim of the partnership was to "identify barriers to cancer screening and research participation among medically underserved minority groups in East Harlem". This paper will describe the relevant community characteristics identified by an assessment undertaken by the community-academic partnership interested in barriers to cancer screening and research participation among medically underserved minority groups.

## Methods

### The Community

East Harlem, located in northern Manhattan and encompassing three zip codes (10029, 10035 and 10037) has a population of 125,076, with 49% Hispanic (of any race); 46% African American; 6% White; and 2% Asian (4). Recent immigrants include those from Mexico, the Dominican Republic, Central America and West Africa, in addition to the predominant Puerto Rican and African American population. East Harlem is characterized by high rates of poverty and unemployment, poor education levels and a high number of single-parent households. In 2000, 37% of the population received Medicaid benefits and 53% of the households are non-English speaking. (4).

### Recruitment of Participants

Men or women over the age of 18, English or Spanish-speaking, able and willing to give consent, who lived, worked and/or sought health care in East Harlem were deemed eligible to participate and recruited in the community at health fairs, tenant associations meetings and senior centers, and at medical clinics of three partnership sites, Settlement Health, Boriken Neighborhood Health Center and Metropolitan Hospital Center. Recruitment and surveys were conducted between June-December 2000 by trained health educators and research interviewers, ethnically and linguistically similar to the residents of East Harlem.

### Measures

The survey was designed to assess both the demographic characteristics of the community, community knowledge of and participation in cancer screening, and potential barriers to screening. The survey battery subscales are listed in Table I. Sociodemographic

characteristics included age; marital and employment status; biological and other children living in the home; education; income; ethnicity; place of birth; time lived in the U.S.; languages spoken; religion and self-rated strength of faith; as well as cancer history; insurance status; access to health care; having a primary care provider; use of emergency departments; and smoking and alcohol use.

Both cancer screening adherence and physician recommendations were assessed. The perceived benefits of and barriers to cancer screening were evaluated with a 23-item likert-style questionnaire with items indicating the potential benefits, such as "Cancer screening is now a very routine medical test", and the potential barriers, e.g., "Getting screened for cancer has a high risk of leading to unnecessary surgery". This scale was based on the work of Rakowski, et al, focusing on the pros and cons of mammography and pap tests (28).

Medical mistrust was examined using a 12-item scale assessing suspicion of mainstream health care systems and health care professionals, as well as the treatment provided to individuals of the respondent's ethnic or racial group (29). Acculturation was measured separately for African American and Hispanic groups with a modified version of the acculturation measure developed by Snowden and Hines previously used in these populations (30). The Powe Fatalism Inventory (31), was used to assess fear, pessimism, predetermination and the inevitability of death associated with cancer and the Jones Temporal Orientation Scale to measure an individual's focus on the past, present or future (32). Attitudes toward and knowledge of genetic testing were evaluated with a 33-item likert scale, including such items as "How much have you heard or read about genetic testing for breast cancer?" and "I would agree to genetic testing for cancer risk if my doctor recommended it".

Only results of the sociodemographic data are discussed herein; results of the other scales will be presented in future reports.

### Procedure

After obtaining informed consent, face-to-face interviews were conducted on-site or at a later date via telephone and lasted approximately one hour in duration. The interviews focused on current knowledge of various screening guidelines, individual screening habits, and potential barriers, such as fatalism, temporal orientation, medical mistrust, cancer worry and family history of cancer. A \$10 phone card or supermarket gift certificate was provided to all participants upon completion of the interview.

Responses were examined in three ways: firstly, a comparison among African Americans, English-language Hispanics and Spanish-language Hispanics; secondly, a sociodemographic comparison based on medical clinic versus community interview site to identify any differences related to those two populations; and thirdly, a comparison of the three clinic sites to examine population differences among these medical sites.

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Insert Table 1 Here

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### Results

#### Response Rate

Of 383 people approached, 248 (65%) agreed to participate in the survey. Significantly more women than men were approached (75% vs. 25%) and agreed to participate (70% vs. 50%). Additionally, a higher portion of people approached in the clinics versus the community declined to participate (45% vs. 11%). No differences in those who agreed to participate versus those who refused were noted in terms of ethnicity or age.

Face-to-face interviews were conducted with 173 (70%) participants; 75 (30%) were completed by telephone. Because African American (n=109) and Hispanic (n=128) participants made up 96% of those surveyed, the results reported herein comprise only these groups.

### Sociodemographic Profile

The sociodemographic characteristics of participants are shown in Table 2. The breakdown, based on self-identified ethnicity and the language of the interview as preferred by the participant, revealed significant differences in the Hispanic sub-groups that would otherwise not have been detected. Spanish-language Hispanics were not born in the U.S. (100% vs. 44% of English-language Hispanics and 16% of African Americans); were less educated (21% postsecondary versus 36% and 38%); had 3 or more children (58% vs. 34 and 46%); are less likely to be employed (87% vs. 64 and 70%); had income under \$10,000 (71% vs. 53 and 41%); and received health care significantly more at one particular clinic, Settlement Health (60% vs. 30 and 35%). Additionally, Hispanics in general were more likely to be Catholic while African Americans were Protestant (92% and 82% vs. 23%). More Hispanics were married or had a partner (38% and 43% vs. 24%). English-language Hispanics were also interviewed in clinics rather than the community (89% vs. 61 and 57%) and were significantly younger than the other two populations ( $x=41.10$ , S.D. 14.1 vs.  $x=50.99$ , S.D. 18.0 for Spanish-language Hispanics and  $x=51.26$ , S.D. 18.9 for African Americans). Post-hoc analyses indicate Spanish-language Hispanics were less likely to be employed and had income under \$10,000 when compared to English-language Hispanics and African Americans ( $p<.05$ ).

### Community/Clinic Comparison

Sociodemographic characteristics based on a comparison of those interviewed in the community versus the medical clinic are presented in Table 3. Important differences are evident: compared to the clinic, the community sample was more African American than Hispanic (59% vs. 40%); over 40 years of age (89% vs. 47%); had more children (57% vs. 40%); more health insurance (93% vs. 80%); were less likely to be married or have a partner (22% vs. 62%); were Protestant (52% vs. 36%); had more access to regular health care (92% vs. 80%); and, if Hispanic, were more likely to be born outside the U.S. (91% vs. 80%). No significant differences were noted in terms of education, income, African American place of birth, or language of interview.

### Clinic Sites Comparison

A third review of demographics between the three medical clinic sites, Settlement Health, Boriken Neighborhood Health Center and Metropolitan Hospital Center, revealed no differences among any sociodemographic variables, with the exception of more Spanish-language Hispanic participants at Settlement Health.

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Insert Table 2 Here

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Insert Table 3 Here

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### Discussion

These findings present relevant community characteristics identified by an assessment of a minority population in an urban, inner-city neighborhood conducted through a community-based, multi-disciplinary initiative, the East Harlem Partnership for Cancer Awareness, designed to increase rates of cancer screening among minority, elderly and other underserved populations.

The success of this endeavor in recruiting hundreds of minority research participants is a testament to the value of a collaborative venture involving an academic medical center and local organizations having credibility within the target community. An existing basis of trust was enhanced through culturally congruent staff involved in recruitment and interview activities, as well as outreach efforts conducted in housing projects where community residents live, senior citizen centers where people socialize, and community clinics, a source of both medical care and information.

Our data confirmed that these East Harlem residents, both African American and Hispanic, had lower socio-economic status, with a sizable majority not working, having income under \$10,000 and government-funded health insurance. Differences between minority groups and within minority sub-groups emerged, with African Americans more likely to be unmarried and having an income over \$10,000. Significant differences between Spanish-speaking Hispanics and both African Americans and English-speaking Hispanics in terms of employment and income point out the importance of acculturation in attempting to understand and affect the health behaviors of medically underserved minority populations.

In spite of the heterogeneity of the Hispanic population in the United States, Hispanics are frequently perceived as a homogeneous group. Within this one community of New York

City, significant variance was found among those self-identifying as Hispanic. Such differences in place of birth, income, education, employment and where clinical services are obtained may affect the knowledge, attitudes, beliefs and behaviors of both groups relative to cancer screening. Because low acculturation levels are related to a fatalistic attitude toward cancer and difficulty communicating with health care professionals, recognition of such differences is critical in the design of interventions to address low rates of cancer screening among Hispanics compared to Whites and African Americans, particularly in terms of meeting the Healthy People 2010 goals for colorectal cancer screening. Interventions targeting English-speaking Hispanics may appropriately reflect the dual acculturation and higher SES of this population, while those targeting less acculturated Spanish-speaking Hispanics may need to be more familial or communal and geared toward a lower literacy, lower SES group.

With the Partnership's objective to develop educational strategies that decrease sociodemographic, institutional and acculturative barriers to cancer screening, recognition of socio-cultural differences between minority groups and within minority sub-groups will facilitate the development of promotional messages and strategies tailored and designed to increase cancer screening in the African American and Hispanic communities. One identified characteristic of both ethnicities, strong faith, may provide another avenue of education through churches and other faith-based groups.

Another major finding of this preliminary study were the issues of recruiting men for surveys and other research activities, including less approachment of men and a higher rate of male refusal. In response, a Partnership study is presently underway to explore the recruitment of men in the Emergency Department at The Mount Sinai Hospital for research participation, while linking them with regular avenues of health care designed to increase access to and

utilization of health care preventive services. Another approach would be to train women to be agents of change within their families/social networks, encouraging expansion of their own commitment to regular cancer screening to husbands, partners, brothers and other family members.

Strength of the research includes community-based cooperation and participation, comprehensive self-report measures, the largely face-to-face interview format with interviewers culturally matched to the population, and sampling at various community sites as well as health clinics. Limitations include the disparity in the recruitment of men and utilization of an interview sample of convenience, thereby precluding generalizability of the findings.

Overall, these findings support the need to develop culturally sensitive and targeted interventions to increase cancer awareness and screening in East Harlem among men and various ethnic sub-groups.

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Table 1**SURVEY BATTERY SUB-SCALES****Section I****Sociodemographics**

(age, marital/employment status, education, children, income, ethnicity,  
place of birth, time in US, language, religion, strength of faith)

**Family Cancer History****Medical Care**

Insurance Status

Primary Care Provider

Use of Emergency Departments

Access to Health Care

**Smoking/Alcohol Use****Section II****Screening**

Knowledge, Practice, Attitudes and Beliefs related to cancers of the  
Breast, Cervix (women), Prostate (men), CRC

MD recommendations

Mammogram anxiety

**Section III****Perceived Cancer Risk**

Worry about Cancer

Medical Mistrust

Genetic Testing

Knowledge, Attitudes, Beliefs

Jones Temporal Orientation Scale

Cancer Fatalism

Acculturation for African Americans, Hispanics, Whites



Table 2

**Sociodemographic Characteristics**  
(n= 237)

	<u>African American</u> (n = 109)		<u>Hispanic</u> Eng. (n = 61)		<u>Hispanic</u> Sp. (n=67)		Significance
	n	(%)	n	(%)	n	(%)	
Gender							
Female	91	(84)	47	(77)	56	(84)	n.s.
Male	18	(16)	14	(33)	11	(16)	
Education							
High school or less	67	(62)	39	(64)	53	(79)	*
At least some college	42	(38)	22	(36)	14	(21)	
Children							
1-2	54	(54)	37	(66)	25	(42)	*
3 or more	46	(46)	19	(34)	34	(58)	
Employed							
Yes	33	(30)	22	(36)	9	(13)	**
No	76	(70)	39	(64)	58	(87)	
Income							
Over \$10,000	61	(59)	27	(47)	17	(29)	***
Under \$10,000	43	(41)	30	(53)	42	(71)	
Insurance							
Government	71	(70)	39	(65)	44	(68)	n.s.
Private	21	(21)	10	(17)	6	(9)	
None	10	(10)	11	(18)	15	(23)	
Marital Status							
Married/Partner	26	(24)	23	(38)	29	(43)	**
Not Married	83	(76)	38	(62)	38	(57)	

Religion Catholic Protestant	21 69	(23) (77)	44 4	(92) (8)	50 11	(82) (18)	***
Faith Strong Not Strong	90 19	(83) (17)	43 17	(72) (28)	36 28	(56) (44)	***
Born in U.S. Yes No	88 17	(84) (16)	34 27	(56) (44)	65	(100)	**
Interview Language English Spanish	105 4	(96) (4)	61	(100)	67	(100)	**
Interview Location Clinic Community Center	62 47	(57) (43)	54 7	(89) (11)	41 26	(61) (39)	**
Settlement Health Boriken Metropolitan	20 31 7	(35) (54) (12)	16 24 13	(30) (45) (25)	24 11 5	(60) (28) (13)	**
Age (18-92)	X = 51.26	S.D. = 18.9	X = 41.10	S.D. = 14.1	X = 50.99	S.D. = 18.0	F (2,234) =7.5, p<.001

\*p &lt; .05.

\*\*p &lt; .01.

\*\*\*p &lt; .001

Table 3

**Community/Clinic Comparison  
Sociodemographic Characteristics  
(n= 237)**

	Community		Clinic		
	n	(%)	n	(%)	Significance
Gender					
Female	66	(78)	135	(83)	n.s.
Male	19	(22)	28	(17)	
Education					
High school or less	59	(69)	103	(63)	n.s.
At least some college	29	(31)	60	(37)	
Children					
1-2	33	(43)	89	(60)	*
3 or more	43	(57)	59	(40)	
Employed					
Yes	18	(21)	51	(31)	n.s.
No	67	(79)	112	(69)	
Income					
Over \$10,000	38	(48)	75	(50)	n.s.
Under \$10,000	41	(52)	75	(50)	
Insurance					
Yes	68	(93)	123	(80)	**
No	5	(7)	31	(20)	
Marital Status					
Married/Partner	19	(22)	101	(62)	**
Not Married	66	(78)	62	(38)	
Religion					
Catholic	37	(48)	81	(64)	***
Protestant	40	(52)	46	(36)	

AA Born in U.S.					
Yes	35	(80)	53	(87)	
No	9	(20)	8	(8)	r
Hispanic Born in U.S.					
Yes	3	(9)	31	(33)	
No	29	(91)	63	(67)	**
Interview Language					
English	56	(66)	120	(74)	
Spanish	29	(34)	43	(26)	n.s.
Health Care Access					
Yes	72	(92)	128	(80)	
No	6	(8)	31	(20)	*
Ethnicity					
African American	47	(59)	62	(40)	
Hispanic	33	(41)	95	(60)	**
Age					
Under 40	9	(11)	86	(53)	
Over 40	69	(89)	75	(47)	****

\*  $p < .02$ \*\*  $p < .01$ \*\*\*  $p < .05$ \*\*\*\*  $p < .001$

The Relationship Between Acute Stress Disorder and  
Posttraumatic Stress Disorder Following Cancer

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Running Head: PTSD AND CANCER

# ABSTRACT

This study investigated the relationship between acute stress disorder (ASD) and posttraumatic stress disorder (PTSD) following cancer diagnosis. Patients who were recently diagnosed with first onset head and neck or lung malignancy ( $N = 82$ ) were assessed for ASD within the initial month following their diagnosis, and reassessed ( $N = 63$ ) for PTSD 6 months following their cancer diagnosis. At the initial assessment, 28% of patients had ASD, and 32% displayed subsyndromal ASD. At follow-up, PTSD was diagnosed in 53% of patients who had been diagnosed with ASD, and in 11% of those who had not met criteria for ASD; 36% of patients with PTSD did not initially display ASD. This study questions the utility of the ASD diagnosis to identify recently diagnosed patients at risk of PTSD.

## The Relationship Between Acute Stress Disorder and Posttraumatic Stress Disorder Following Cancer

Acute stress disorder (ASD) was introduced in the fourth edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV; American Psychiatric Association, 1994) to describe trauma responses in the initial month following a traumatic event. A primary purpose of the ASD diagnosis was to identify individuals in the initial trauma phase who would subsequently develop posttraumatic stress disorder (PTSD; Koopman, Classen, Cardeña, & Spiegel, 1995). The requisite symptoms to meet ASD include three dissociative symptoms (including emotional numbing, reduced awareness of one's surroundings, derealization, depersonalization, and dissociative amnesia), one reexperiencing symptom, marked avoidance, marked anxiety or increased arousal, and evidence of significant distress or impairment. The disturbance must last for a minimum of 2 days and a maximum of 4 weeks, after which time a diagnosis of PTSD should be considered. Apart from the earlier timeframe, the major difference between ASD and PTSD is the former's emphasis on dissociative reactions to the trauma. The emphasis on dissociation in ASD is based on the proposition that dissociation during trauma impedes optimal encoding and organization of trauma memories, and consequently contributes to psychopathology (Koopman et al., 1995).

DSM-IV also recognized, for the first time, that PTSD may be precipitated by life-threatening illness. This development has resulted in a number of studies on the incidence of PTSD in adult cancer patients, with incidence of cancer-related PTSD ranging from 0% to 32% (for a review, see Kangas, Henry, & Bryant, 2002). Only two published studies have assessed the incidence of ASD in adult cancer patients. Whereas McGarvey and her colleagues (1998) reported a 33% incidence rate of ASD in a heterogeneous sample of newly diagnosed cancer patients, Green and her colleagues (1998) reported a nil incidence rate for ASD in their sample

of early stage breast cancer patients. This latter finding may have been influenced, however, by the retrospective assessment of ASD conducted on average 6 months following treatment completion. To date, no research has prospectively examined the relationship between ASD and PTSD following cancer.

There are several important reasons to index the predictive capacity of the ASD diagnosis following cancer. First, the potentially poor prognosis and aversive treatment side-effects may influence the course of psychological adjustment following cancer. Second, the ASD diagnosis has been strongly debated on conceptual and empirical grounds (Harvey & Bryant, 2002). There are now nine prospective studies describing the relationship between ASD and PTSD (for a review, see Bryant, in press). Although the majority of studies indicate that approximately 80% of individuals with ASD subsequently develop PTSD, these same studies indicate that many people develop PTSD without initially displaying ASD (e.g., Brewin, Andrews, Rose, & Kirk, 1999; Bryant & Harvey, 1998; Harvey & Bryant, 1998). Accordingly, there is a need to determine the ability of the ASD diagnosis to predict PTSD in recently diagnosed cancer patients.

This study represents the first prospective investigation of ASD and PTSD following cancer. The study focused on head, neck and lung cancer patients because they are susceptible to high rates of distress following their cancer diagnosis relative to other cancer populations (Zambora, Brintzenhofesoc, Curbow, Hooker, & Piantadosi, 2001). We initially assessed participants within one month of their cancer diagnosis because this is the timeframe of the ASD diagnosis. We re-assessed participants 6 months after cancer diagnosis because prospective studies indicate that most natural remission of posttraumatic stress occurs within this time (Rothbaum, Foa, Riggs, Murdock, & Walsh, 1992), and this is the timeframe of previous studies investigating the relationship between ASD and PTSD (Bryant, in press).

#### Method



### *Participants*

Eighty-two patients who were consecutive hospital admissions (61 males, 21 females) diagnosed with first onset head, neck or lung cancer were assessed within 1 month following their cancer diagnosis and prior to commencing treatment. Patients were recruited from a medical oncology unit at a major metropolitan hospital. Exclusion criteria included (a) inability to comprehend all interview questions without the aid of an interpreter, (b) brain metastases at time of diagnosis, (c) prior history of significant brain impairment, (d) history of psychotic illness, (e) significant concurrent non-cancer medical problems at diagnosis, and (f) age less than 18 years. The sample comprised 56 head and neck cancer patients (HNC) ( $M = 57.5$  years,  $SD = 12.3$ ; 44 males 12 females) and 26 lung cancer patients (LGC) ( $M = 65.6$  years,  $SD = 10.3$ ; 17 males and 9 females).

At assessment, 27% of participants were diagnosed with stage 1 (21 HNC and 1 LGC), 11% were diagnosed with stage 2 (4 HNC and 5 LGC), 52% were diagnosed with stage 3 (26 HNC and 17 LGC), and 10% were diagnosed with stage 4 cancer (5 HNC and 3 LGC) [indexed according to the International Union Against Cancer Classifications (UICC) system]. In terms of education, 28% left school before high school, 52% completed high school, and 20% completed tertiary education. In addition, 59% of the sample were married, 18% were separated or divorced, 17% were single, and 6% were widowed. At assessment, 41% were employed, 2% were unemployed, 42% were retired, and 15% were on disability pensions. In terms of ethnic origin, there was a variety of Anglo-Saxon ( $n = 70$ ), Mediterranean ( $n = 5$ ), Asian ( $n = 4$ ), African ( $n = 1$ ), South American ( $n = 1$ ), and Maori ( $n = 1$ ).

At 6 months post-cancer diagnosis, attempts were made to contact participants by telephone. Six participants (5 LGC and 1 HNC) had died; 4 (3 LGC and 1 HNC) were seriously ill due to either treatment complications, deterioration of physical health status and/or disease metastasis; 8 (4 LGC and 4 HNC) declined to be interviewed; and 1 LGC participant was unable

to be contacted. In total, 63 participants took part in the follow-up assessment, which represented 77% of the initial sample [50 HNC (38 males and 12 females) and 13 (8 males and 5 females) LGC patients]. Participants were assessed on average 6 months following their diagnosis ( $M = 180.27$  days,  $SD = 27.08$ ), and 3 months following the completion of their treatment ( $M = 88.68$  days;  $SD = 46.87$ ). No differences were found between those who participated in the 6 month follow-up assessment compared to non-participants in terms of age, gender, type and stage of cancer, prognosis, treatment, acute stress severity, and premorbid psychological history. Fewer LGC patients (50%) were re-assessed at 6 months follow-up than HNC patients (89%) [ $\chi^2 (1,63) = 13.27, p < .001$ ].

#### *Procedure*

Following written informed consent, a clinical psychologist administered the initial assessment during an outpatient visit to the hospital within one month of cancer diagnosis. Patients were assessed for ASD utilizing the Acute Stress Disorder Interview (ASDI; Bryant, Harvey, Dang, & Sackville, 1998). The ASDI is a structured clinical interview that is based on DSM-IV criteria, and possesses sound test-retest reliability ( $r = 0.95$ ), sensitivity (92%), and specificity (93%). A clinical psychologist also conducted the 6-month assessment, which assessed for PTSD using the Clinician Administered PTSD Scale – Form 1 (CAPS-1; Blake, Weathers, Nagy, Kaloupek, Gusman, Charney, & Keane, 1995). The CAPS possesses good sensitivity (.84) and specificity (.95) relative to the SCID PTSD diagnosis, and also possesses sound test-retest reliability (.90-.8) (Blake et al., 1995). All assessments were conducted on an out-patient basis; 40 (64%) participants were assessed in person, and 23 (36%) were assessed via telephone because they lived in rural areas. There were no differences between participants who were assessed in person or by telephone in terms of ASD severity or medical variables. Both the ASDI and the CAPS-1 were administered with the instruction to respond to each question with reference to their cancer as the precipitating stressor.

## Results

### *Incidence of ASD and PTSD*

Table 1 presents the percentage of participants who met full diagnostic criteria for ASD and PTSD in the initial month and at 6 months post-cancer diagnosis, respectively. Twenty-three (28%) participants met full diagnostic criteria for ASD and 26 (32%) met all but one cluster of the DSM-IV criteria. The latter group was considered as qualifying for a subsyndromal diagnosis. Paired chi-square analyses indicated that more females (57%,  $n = 12$ ) than males (18%,  $n = 11$ ) met criteria for ASD ( $\chi^2 = 11.84$ ,  $df(1,80)$ ,  $p < 0.01$ ). Planned comparisons also indicated that participants with ASD were younger ( $M = 54.4$ ;  $SD = 12.2$ ) than those who did not have ASD ( $M = 62.3$ ;  $SD = 11.6$ ) ( $t(1, 80) = 2.74$ ,  $p < 0.05$ ). There were no group differences in terms of type or stage of cancer, prescribed cancer treatment, time between diagnosis and assessment, and interval between assessment and anticipated date of commencement of cancer therapy.

At 6 months post-cancer diagnosis, 14 (22%) participants met full diagnostic criteria for PTSD, and 10 (16%) met all but one cluster of the PTSD criteria. More females (47%,  $n = 8$ ) than males (13%,  $n = 6$ ) met criteria for PTSD ( $\chi^2 = 8.31$ ,  $N = 63$ ,  $df=1$ ,  $p < 0.05$ ). Patients with PTSD were younger ( $M = 49.5$ ,  $SD = 12.5$ ) than patients without PTSD ( $M = 61.3$ ,  $SD = 11.8$ ) ( $t(1, 61) = 3.27$ ,  $p < 0.05$ ). There were no group differences however, in terms of cancer status or treatment effects.

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Insert Table 1 about here

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*Relationship Between ASD and PTSD*

Among the individuals who completed both assessments, 53% of those who were diagnosed with ASD, met criteria for PTSD at 6 months follow-up (see Table 1). In terms of participants who did not meet criteria for ASD, 11% met PTSD criteria at 6 months. Further, 36% of participants who subsequently developed PTSD did not initially meet full criteria for ASD.

*Predictive Power of ASD Symptoms*

Table 2 also presents the positive and negative predictive power of developing PTSD at 6 months post-cancer diagnosis. Positive predictive power was defined as the probability of developing PTSD when an ASD symptom was present. This probability was calculated by dividing the number of individuals who reported each ASD symptom and who later met criteria for PTSD, by the total number of participants who reported each ASD symptom. Conversely, negative predictive power was defined as the probability that an individual would not develop PTSD when an ASD symptom was absent. This probability was calculated by dividing the number of individuals who did not report each ASD symptom and who later did not meet criteria for PTSD, by the total number of participants who did not report each ASD symptom. Negative predictive power was strong for fear, numbing, recurrent images and thoughts, distress to cancer-related cues, avoidance of distress, irritability, and motor restlessness. Positive predictive power was generally weaker; numbing, reduced awareness, depersonalization, dissociative amnesia, reliving the experience, avoidance behaviour, exaggerated startle response, and motor restlessness had positive predictive power of at least .50.

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Insert Table 2 about here  
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*Improving Prediction of PTSD*

The eight ASD symptoms that had at least positive predictive power of 0.50 were entered into a stepwise logistic multiple regression in order to predict PTSD caseness at 6 months follow-up. These variables comprised emotional numbing, reduced awareness, depersonalisation, amnesia, a sense of reliving, avoidance of cancer cues, startle response, and motor restlessness. Emotional numbing, a sense of reliving, and motor restlessness symptoms in the acute trauma phase were found to be significant predictor variables of PTSD at 6 months following cancer diagnosis. These three variables correctly classified 89% of participants overall, including 79% of individuals with PTSD and 92% without PTSD (Model  $\chi^2 = 30.95$ ,  $df = 3$ ,  $p < .001$ ).

*Discussion*

The observed incidence of ASD and PTSD in the current study is consistent with previously reported rates of these disorders following cancer diagnosis (Jacobsen et al., 1998; McGarvey et al., 1998; Naidich & Motta, 2000). The major finding of this study involves the relationship between ASD and PTSD. The observation that 53% of those patients who initially displayed ASD subsequently developed PTSD, and that 36% of people who eventually developed PTSD did not meet ASD criteria in the acute phase suggests that the ASD diagnosis had only modest predictive power for identifying recently diagnosed people who will develop PTSD. This finding reinforces other studies that have challenged the utility of the ASD diagnosis as a predictor of chronic PTSD (see Brewin, Andrews, & Rose, 2003; Bryant in press; Harvey & Bryant, 2002). The limited predictive power of the ASD diagnosis also concurs with increasing evidence that acute dissociation does not necessarily predict subsequent PTSD (Marshall & Schell, 2002).

Across the ASD symptoms, emotional numbing, a sense of reliving the experience, and motor restlessness were the best predictors of subsequent PTSD. Previous work has indicated that chronic PTSD can be predicted by initial emotional numbing (Bryant & Harvey, 1998;

Harvey & Bryant, 1998); intense reexperiencing of the trauma (Brewin et al., 1999; Harvey & Bryant, 1998), and motor restlessness (Harvey & Bryant, 1998). Considering that numbing has been conceptualized as a compensatory reaction to hyperarousal (Foa, Zinbarg, & Rothbaum, 1992), it appears that initial symptoms involving hyperarousal are important in predicting PTSD. In this sense, the predictive power of these three symptoms accord with biological models that propose that PTSD is strongly mediated by intense fear conditioning and hyperarousal reactions after trauma exposure (Yehuda, McFarlane, & Shalev, 1998).

We recognize that the course of adaptation following cancer diagnosis may not be comparable to adaptation following other forms of trauma. The often-protracted nature of the cancer experience, the side-effects of treatments, and uncertainty about the prognosis may have caused a significant proportion of patients who did not initially experience ASD to subsequently develop PTSD. Conversely, the completion of initial cancer treatment during the 6 months after diagnosis may have assisted some of those who initially displayed ASD to adapt. Although medical variables were not associated with ASD or PTSD status in the current study, it is possible that cancer-related factors may have influenced the psychological course.

We acknowledge that conclusions from this study are limited by a number of methodological factors. First, our findings do not necessarily generalize to other cancer or non-medical trauma populations. Second, our small sample size and attrition during follow-up limits inferences. In this context, the loss of 50% of LNC patients at follow-up raises the possibility that attrition biased the results. The small sample size also limited interpretation of apparent gender and age differences between those who did and did not develop PTSD. Third, our follow-up period was relatively short, particularly in the context of the brief period of time that had elapsed since initial cancer-treatment was completed. Fourth, the use of telephone interviews for a proportion of participants may have influenced our findings. Fifth, future studies should

attempt to include equal numbers of male and female participants to more accurately index the role of gender in posttraumatic adjustment to cancer.

In summary, these findings point to the complex course of psychological responses experienced after cancer diagnosis. Although the ASD diagnosis had only modest predictive power for identifying patients who later developed PTSD, we recognize that stress reactions following cancer have a distinctive course and these findings may have limited generalizability to other trauma populations. The relatively high incidence of PTSD at 6-months following one's cancer diagnosis and on average 3 months following treatment completion points, to the need for accurate identification of these patients, and the need for development of validated interventions to assist the psychological sequelae of cancer.

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Table 1

Percentage of Participants With Full, Subsyndromal and No Acute Stress Disorder (ASD)

Diagnoses Who Met Criteria for Full and No Posttraumatic Stress Disorder (PTSD)

ASD			PTSD			
Criteria Met	n	%	No. contacted	Criteria Met	n	%
Full	23	28	17	Full	9	53
				None	8	47
Subsyndromal	26	32	23	Full	4	17
				None	19	83
None	33	40	23	Full	1	4
				None	22	96

Table 2

Percentage of Participants With Full Posttraumatic Stress disorder (PTSD) and No PTSD for Each Acute Stress Disorder (ASD) Symptom and the Positive and Negative Predictive Power of Each Symptom

ASD Symptom	Positive Predictive Power <sup>a</sup>	Negative Predictive Power <sup>b</sup>
Fear	0.39	0.94
Helplessness	0.31	0.89
Numbing	0.50	0.95
Reduced awareness	0.56	0.89
Derealization	0.40	0.86
Depersonalization	0.53	0.88
Dissociative amnesia	0.53	0.89
Recurrent thoughts	0.35	0.96
Nightmares	0.33	0.79
Reliving experience	0.62	0.88
Distress on exposure	0.43	0.94
Avoidance of thoughts	0.31	0.89
Avoidance of talk	0.30	0.83
Avoidance of cues	0.63	0.84
Avoidance of distress	0.32	0.95
Difficulty sleeping	0.38	0.89
Irritability	0.41	0.94
Poor concentration	0.41	0.88

Table 2 (Continued)

Percentage of Participants With Full PTSD and No PTSD Reporting Each ASD Symptom and the Positive and Negative Predictive Power of Each Symptom

ASD Symptom	Positive	Negative
	Predictive Power <sup>a</sup>	Predictive Power <sup>b</sup>
Hypervigilance	0.33	0.83
Startle response	0.57	0.88
Motor restlessness	0.52	0.93

Note. <sup>a</sup> The probability of the presence of PTSD when the symptom is present.

<sup>b</sup> The probability of the absence of PTSD when the symptom is absent.

## Correlates of Acute Stress Disorder in Cancer Patients

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Running Head: ASD Correlates and Cancer

## ABSTRACT

This study investigated the correlates of acute stress disorder (ASD) following a diagnosis of cancer in adults. Individuals who were recently diagnosed with first onset head and neck or lung malignancy ( $n = 82$ ) were assessed within one month of diagnosis using the Acute Stress Disorder Interview, and the Structured Clinical Interview for DSM-IV to index the incidence of ASD and other affective and anxiety disorders following their cancer diagnosis. Participants were also administered several self-report measures including the European Organization for Research and Treatment of Cancer - Core questionnaire, Mini-Mental Adjustment to Cancer Scale, Peri-Traumatic Dissociative Experiences Questionnaire, Beck Depression Inventory (Second Edition), State Trait Anxiety Inventory, Post-Traumatic Cognitions Inventory, and the Duke-UNC Functional Social Support scale. ASD was diagnosed in 28% of participants, whilst almost a quarter of the sample (23%) met criteria for other anxiety and/or depression disorders following their cancer onset. Acute stress severity was associated with elevated dissociative responses at the time of receiving one's cancer diagnosis, decline in cognitive functioning, and an increase in emotional distress within the initial month following one's diagnosis. This study provides evidence for identifying recently diagnosed cancer patients who may benefit from psychological assistance.

### Correlates of Acute Stress Disorder in Cancer Patients

The fourth edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV; American Psychiatric Association, 1994) recognized for the first time that posttraumatic stress disorder (PTSD) may be precipitated by life-threatening illness, such as being diagnosed with cancer. This development has contributed to greater focus in recent years on the issue of PTSD following a diagnosis of cancer. Notably, 16 published studies to date have assessed PTSD caseness in adult cancer patients, and reported current incidence of cancer-related PTSD ranging from 0% (Mundy et al., 2000) to 55% (Khalid & Gul, 2000) at the time of the assessment. Participants in these studies were assessed at variable times between 3 weeks and 11 years following treatment completion (see Kangas, Henry, & Bryant, 2002 for review).

Acute stress disorder (ASD) was introduced in DSM-IV (American Psychiatric Association, 1994) to describe acute traumatic stress responses that may occur in the initial month following a trauma, and, to identify individuals at risk of developing PTSD (Classen, Koopman, & Spiegel, 1993; Koopman, Classen, & Spiegel, 1994). ASD is distinguished from PTSD by its greater emphasis on dissociative symptoms. Nine studies to date, have prospectively assessed the relationship between ASD in the initial month after trauma, and subsequently assessed the development of PTSD (Brewin, Andrews, Rose, & Kirk, 1999; Bryant & Harvey, 1998; Harvey & Bryant, 1998, 1999, 2000; Holeva, Tarrier, & Wells, 2001; O'Donnell, Creamer, Pattison, & Atkin, 2001; Schnyder, Moergeli, Klaghofer, & Buddeberg, 2001; Staab, Grieger, Fullerton, & Ursano, 1996; also see Bryant (in press), for review). In terms of individuals who initially met diagnostic criteria for ASD, a significant number of studies have found that approximately 80% of people with ASD subsequently



developed PTSD (e.g., Brewin et al., 1999; Bryant & Harvey, 1998; Harvey & Bryant, 1998, 1999, 2000). Conversely, across the majority of studies, less than 50% of individuals who developed PTSD did not initially meet ASD criteria (e.g., Bryant & Harvey, 1998; Harvey & Bryant, 1998, 1999; O'Donnell et al., 2001; Schnyder et al., 2001; Staab et al., 1996).

Only two published studies have assessed the incidence of ASD in adult cancer patients. Although Green and her colleagues (1998) found that 5% of their sample of early stage breast cancer patients met criteria for cancer-related PTSD, they reported a nil incidence rate for ASD. These findings may have been influenced, however, by the retrospective assessment of ASD conducted on average 6 months following treatment completion. The second study conducted by McGarvey and her colleagues (1998) assessed the incidence of ASD in a heterogeneous sample of newly diagnosed cancer patients, and reported an incidence rate of 33%.

Being diagnosed with cancer represents a distinctive stressor within the ASD/PTSD framework because it involves a potentially chronic and debilitating illness that may be accompanied by a range of aversive associated events, including the severity of diagnosis, prognosis, noxious treatments, disfigurements and dysfunctions, and disruptions to one's physical, social and occupational functioning. The stressor associated with being diagnosed with cancer is also unique because it is triggered by an internally induced event rather than an external source of threat (Green et al., 1998). Similarly, the threat to one's physical integrity following a diagnosis of cancer is not necessarily immediate, therefore, the threat of the stressor is ongoing. That is, whereas most precipitants of PTSD are external and discrete prior events that pose a time-limited threat, cancer represents a protracted and internally

based stressor. This issue is highlighted by DSM-IV's description of the stressor as a past-orientated event. One implication of this perspective is that the diagnosis of cancer itself (i.e., past-oriented) is regarded as the stressor rather than the array of potential threats that are ongoing. Ambiguity over the specific cause of PTSD in this population may cause variability in diagnosis of PTSD because of divergent definitions of the stressor.

The potential of the ASD diagnosis to predict PTSD following a traumatic incident, including a diagnosis of cancer, has important implications for traumatized individuals for whom early interventions may minimize or even prevent subsequent PTSD and comorbid psychopathology. Studies that have examined the predictors of acute posttraumatic stress responses following discrete traumas (e.g., motor vehicle accidents) have found that premorbid psychological disorders (Barton, Blanchard, & Hickling, 1996; Harvey & Bryant, 1999), including prior history of PTSD (Harvey & Bryant, 1999), avoidant coping style (Harvey & Bryant, 1998), comorbid depression (Harvey & Bryant, 1998, 1999), and younger age (Harvey & Bryant, 1998) were significant predictors of ASD. In contrast, only one published study has examined the incidence and predictors of ASD following cancer. Specifically, McGarvey et al. (1998) found that younger age, no prior life-threatening illness, low social support from friends, and dissatisfaction with how the diagnosis was communicated were significant predictors of ASD in females; but no variables were predictive of ASD in males. Conclusions from this research are limited, however, by the study's reliance on self-report measures and the timing of the assessment during the course of the patients' treatment regimens. That is, considering the potentially vast array of side-effects associated with conventional cancer treatments (i.e., surgery, radiotherapy, and chemotherapy), including fatigue, appetite loss, nausea, concentration difficulties, and sleep

disturbances, assessing patients psychological well-being whilst they are still undergoing treatment is potentially problematic because it is difficult to delineate between symptoms arising from the treatment side-effects compared to symptoms reflecting poor psychological functioning.

Accordingly, the aim of our present study was to investigate the correlates of acute trauma response in newly diagnosed head, neck and lung cancer patients within the initial month following their cancer diagnosis and prior to the commencement of their cancer treatments. This study focused on head, neck and lung cancer patients because they are susceptible to high rates of distress following their cancer diagnosis compared to other cancer patients (Morton, Davies, Baker, Baker, & Stell, 1984; Hammerlid et al., 1999; Zabora, Brintzenhofesoc, Curbow, Hooker, & Piantadosi, 2001). Moreover, given the paucity of research examining acute stress responses within this population, in the present study we adopted an exploratory design in examining the potential correlates of ASD in newly diagnosed cancer patients. On the basis of the trauma literature, we specifically examined common variables associated with acute traumatic responses following a life-threatening event including psychiatric history (particularly premorbid PTSD), comorbid psychological problems, coping style and cognitive attributions, social support, age, gender, and severity of stressor (in this instance, stage of disease and prognosis at diagnosis).

## Method

### *Participants*

Eighty-two patients (61 males, 21 females) who were diagnosed with first onset head, neck or lung cancer were assessed within 1 month following their cancer diagnosis ( $M = 19.66$  days;  $SD = 8.07$ ) and prior to commencing treatment. Patients were recruited

from a medical oncology unit at a major metropolitan hospital in Sydney. Exclusion criteria included (a) inability to comprehend all interview questions without the aid of an interpreter, (b) brain metastases at time of diagnosis, (c) prior history of significant brain impairment, (d) history of psychotic illness, (e) significant concurrent non-cancer medical problems at diagnosis, and (f) age less than 18 years. The sample ranged in age from 24 to 84 years ( $M = 60.1$  years,  $SD = 12.2$ ), and comprised 56 head and neck cancer patients ( $M = 57.5$  years,  $SD = 12.3$ ) and 26 lung cancer patients ( $M = 65.6$  years,  $SD = 10.3$ ). At assessment, 27% of participants were diagnosed with stage 1, 11% were diagnosed with stage 2, 52% were diagnosed with stage 3, and 10% were diagnosed with stage 4 cancer (indexed according to the International Union Against Cancer Classifications (UICC) system). In terms of education, 28% left school before high school, 52% completed high school, and 20% completed tertiary education. In addition, 59% of the sample were married, 18% were separated or divorced, 17% were single, and 6% were widowed. At assessment, 41% were employed, 2% were unemployed, 42% were retired, and 15% were on disability pensions. One participant was of New Zealand origin, one was South American, one was South African, four were of Asian origin, five were Mediterranean, and 70 were of Anglo-Saxon origin.

### *Procedures*

Participants were in the first instance invited to take part in the research by a member of the medical oncology team at the Prince of Wales Hospital, Sydney. Following informed consent, a clinical psychologist interviewed participants (**Richard how should I phrase my qualifications**) within the initial month following their cancer diagnosis and prior to commencing treatment for their disease. Presence of ASD was assessed using the Acute Stress

Disorder Interview (ASDI; Bryant, Harvey, Dang, & Sackville, 1998), which is a structured clinical interview based on DSM-IV criteria and possesses sound test-retest reliability ( $r = 0.95$ ), sensitivity (92%), and specificity (93%). The ASDI contains 19 dichotomously scored items that relate to the DSM-IV ASD symptoms, and provides a total score indicative of acute stress severity (ASS; range 0 to 19). The Anxiety, Mood and Substance Use modules of the Structured Clinical Interview for DSM-IV (SCID - DSM-IV; First, Spitzer, Gibbon, & Williams, 1996) were administered to assess both lifetime (pre-cancer diagnosis) and current (post-cancer diagnosis) incidence of psychological disorders.

Participants were also administered a series of questions that indexed whether any other member of their family (genetic) had been diagnosed with any type of cancer, and whether they had been diagnosed with any other prior life-threatening illness. In addition, participants were asked to rate on a 10-point Likert scale (1 = "definitely not to blame", 10 = "definitely to blame") (a) the extent to which they believed that they were personally to blame for their cancer occurring, and (b) the extent to which they attributed blame for their cancer occurring to someone or something else. Individuals were also asked to rate their prognosis on a 10-point Likert scale (1 = "expecting the worst outcome in terms of prognosis", 10 = "definitely will recover from cancer").

Participants were then administered the following seven questionnaires.

(1) *European Organization for Research and Treatment of Cancer - Core questionnaire* (EORTC QLQ-C30; Aaronson et al., 1993) is a 30-item quality-of-life measure that consists of five functional scales (physical, role, cognitive, emotional and social functioning), three symptom scales (fatigue, pain, and nausea and vomiting), a global perceived health and

quality-of-life (QoL) scale, and a number of single items indexing additional symptoms commonly reported by cancer patients (such as dyspnea and appetite loss).

(2) *Mini-Mental Adjustment to Cancer Scale* (Mini-MAC; Watson et al., 1994) contains 29 items relating to 5 subscales (Hopelessness/Helplessness; Anxious Preoccupation, Cognitive Avoidance, Fatalism, and Fighting Spirit) that assess the coping style of cancer patients following their diagnosis.

(3) *Peritraumatic Dissociative Experiences Questionnaire* (PDEQ; Marmar, Weiss, & Metzler, 1998) is a 10-item self-report measure that elicits responses on a five-point Likert scale (1 = "Not at all true"; to 5 = "Extremely true") regarding the extent to which individuals experienced peritraumatic dissociation symptoms at the time of the trauma (in this instance, at the time patients were told their cancer diagnosis).

(4) *Beck Depression Inventory – Second Edition* (BDI-II; Beck, Steer, & Brown, 1996) is a 21-item questionnaire that adheres to the Major Depression Disorder criteria in DSM-IV, and indexes depression severity.

(5) *State Trait Anxiety Inventory* (Form Y) (STAI-Y; Spielberger, Gorsuch, Lushene, Vagg, & Jacobs, 1983) comprises 40 items relating to 2 subscales assessing state and trait anxiety.

(6) *Post-Traumatic Cognitions Inventory* (PTCI; Foa, Ehlers, Clark, Tolin, & Orsillo, 1999) is a 33-item self-report measure of trauma-related thoughts and beliefs which comprise 3 subscales; Negative Cognitions about Self, Negative Cognitions about World, and Self-blame. In the present study, the items on this measure pertained to participants' cognitions following their cancer diagnosis.

(7) *Duke-UNC Functional Social Support Scale* (DUKE-SS; Broadhead, Gehlbach, de Gruy & Kaplan, 1988) is an 8-item measure designed to assess functional elements of perceived

quality of social support that individuals report to be receiving following a particular event. In contrast to the other six self-report instruments where a high score indicated poor psychological functioning including negative cognitive attributions, a high score on the DUKE-SS denotes high perceived quality of social support, whilst a low score represents poor perceived quality of social support received from family and close friends following one's cancer diagnosis.

## Results

### *Incidence of ASD*

ASD was diagnosed in 28% ( $n = 23$ ) of participants within the initial month following their cancer diagnosis, and prior to the commencement of treatment. No differences were observed between the ASD and No-ASD groups in terms of participants' type and stage of malignancy, prescribed cancer therapy, and length of time between diagnosis and assessment. Participants with ASD were significantly younger ( $M = 54.36$  years,  $SD = 12.21$ ) than their non-ASD counterparts ( $M = 62.27$  years,  $SD = 11.61$ ;  $t(1,80) = 2.74$ ,  $p < 0.01$ ). In addition, a greater proportion of females (57%) met criteria for ASD than males (18%;  $\chi^2 = 11.84$ ,  $df(1,80)$ ,  $p < 0.01$ ).

### *Cancer-Related ASD and Psychological Comorbidity*

The incidence of lifetime (non-cancer related) major depressive disorder (MDD) (31%), anxiety disorders (45%) and alcohol and substance-use (40%) disorders was relatively high in this sample. The high incidence of lifetime anxiety disorders was primarily due to the high proportion of patients who had met criteria for PTSD (16%) and specific phobia disorders (15%) prior to their cancer onset. The only significant difference

between participants in terms of lifetime incidence of psychological disorders was that a greater proportion of individuals in the ASD group (35%) had met criteria for non-cancer related PTSD prior to their cancer onset compared to individuals with no-ASD [9%;  $\chi^2 = 6.73$ ,  $df(1,80)$ ,  $p < .01$ ].

Almost a quarter of the sample met criteria for MDD ( $n = 28$ ) following their cancer diagnosis. Significantly more ASD patients (48%) met MDD criteria than no-ASD participants [14%;  $\chi^2 = 9.08$ ,  $df(1,80)$ ,  $p < .01$ ]. In addition, nearly a quarter of the sample ( $n=23$ ) met criteria for non-cancer related anxiety disorders following their cancer diagnosis, which were primarily due to chronic specific phobia disorders (13%). Only a small proportion (2%) of individuals continued to meet criteria for an alcohol-related disorder following their cancer diagnosis.

#### *Prediction of ASD Severity and Caseness*

Table 1 presents the correlation coefficients that were calculated between all potential independent variables collected at the initial assessment and Acute Stress Severity (ASS), in order to select appropriate sets of variables to enter into a multiple regression model to predict ASS. This method was adapted from Blanchard et al.'s (1996) methodology utilized in the first systematic attempt at prediction of PTSD severity following trauma in survivors of motor vehicle accidents. In the present study, the ASS was defined by the total ASDI score. The eight independent variables that most strongly correlated with ASS were included into this equation; these variables included PDEQ, BDI-II, EORTC QLQ-C30 – Emotional subscale, Mini-MAC Anxious Preoccupation, EORTC QLQ-C30 – Cognitive Functioning scale, STAI-Y Trait subscale, STAI-Y State subscale, and DUKE-SS



score. Due to the exploratory nature of the study design, these variables were entered into a forward stepwise multiple regression with ASS as the dependent variable. Table 2 presents a summary of the multiple regression analysis. Elevated PDEQ, EORTC QLQ-C30 – Cognitive Functioning, and EORTC QLQ-C30 – Emotional Functioning scores at cancer-diagnosis were the best predictors of ASS, accounting for 70.6% of the variance.

### Discussion

The significant predictors of ASD severity were elevated dissociative responses at the time of receiving one's cancer diagnosis, decline in cognitive functioning, and an increase in emotional distress within the initial month following one's diagnosis. The percentage of variance accounted for by the multiple regression model (70.6%) was relatively high, and was considerably greater than the ASD predictor model reported by McGarvey et al. (1998) that accounted for 46% of the variance in predicting ASS within their heterogeneous subsample of female cancer patients. Notably, there were no common variables associated with ASS following cancer between McGarvey et al.'s and the present study. This disparity may be partly attributed to the differences in methodology between the two studies, including different cancer populations.

The finding that heightened dissociative responses at the time participants received their cancer diagnosis contributed to more than half (58.5%) of the variance in accounting for ASS is hardly surprising because dissociative reactions are a predominant and necessary criteria for ASD. This finding also concurs with evidence of an association between peritraumatic dissociative responses and stress reactions (e.g., Holen, 1993; Koopman et al., 1994; Marmer et al., 1994; Shalev, Peri, Canetti, & Schreiber, 1996; Ursano et al., 1999).

The reported decline in memory and concentration accounted for 8.5% of the variance in ASS. The association with concentration deficits may be attributed to (a) the inclusion of concentration deficits in the ASD criteria, (b) fatigue-related factors associated with the cancer contributing to cognitive deficits in the ASD participants, or (c) the interference of intrusions and anxiety on cognitive abilities. In this context, it is noteworthy that there is strong evidence that posttraumatic anxiety is associated with attention and memory deficits (Bremner et al., 1993; Dalton, Pederson, & Ryan, 1989).

The finding that psychological distress was a predictor of ASS is consistent with the observation that more participants with ASD also met criteria for comorbid MDD (48%) following their cancer diagnosis. This result concurs with the trauma literature that has commonly found a relationship between comorbid depression and PTSD following trauma (Blanchard, Buckley, Hickling, & Taylor, 1998; Shalev et al., 1998) including cancer (Mundy et al., 2000). Further, significantly more ASD participants met criteria for lifetime non-cancer related PTSD (35%), than individuals with no-ASD (9% non-cancer PTSD). This outcome converges with other studies that have found that premorbid psychological problems prior to subsequent trauma exposure has been associated as a risk factor in the development and maintenance of PTSD in discrete non-medical trauma (e.g., Barton et al., 1996; Blanchard et al., 1996; Breslau, Davis, Andreski, & Peterson, 1991) and cancer (Mundy et al., 2000) populations.

Prior research has shown that a high proportion of individuals diagnosed with head, neck, and lung carcinomas have had a premorbid history of consuming large quantities of alcohol and other illicit substances (Duffy et al., 2002; Kugaya et al., 2000). The present findings are consistent with this research, particularly as a high proportion of patients met

lifetime incidence for alcohol and substance-related disorders (40%), whilst only a minority of individuals (2%) continued to meet criteria for alcohol-related disorders following their cancer diagnosis. This latter finding is interesting in the context of the non-medical trauma literature, which has shown that individuals with PTSD are at elevated risk of developing comorbid alcohol and substance use disorders post-trauma, and has been interpreted as reflecting a maladaptive coping style (Breslau et al., 1991; Jacobsen, Southwick, & Kosten, 2001; Kessler, Sonnega, Bromet, Hughes, & Nelson, 1995). One possible explanation for the lower incidence of alcohol-related disorders following cancer diagnosis is that patients are strongly encouraged to reduce the consumption of alcohol and smoking at diagnosis. Considering that the diagnosis of cancer is a major stressor in itself, newly diagnosed cancer patients may in the short-term be more prone to abstain or at least reduce their alcohol consumption in order to potentially minimise additional health threats. The ability to maintain abstinence from alcohol (and smoking) has however, been found to be problematic in the longer-term for cancer patients (Duffy et al., 2002; Ostroff et al., 1995).

In summary, peritraumatic dissociative responses, decline in cognitive functioning, and emotional distress are associated with an acute stress response following cancer, irrespective of one's diagnostic status, and physical functioning at diagnosis. This latter finding concurs with other cancer studies that have found no significant association between type, severity, stage and prognosis of cancer and severity of posttraumatic stress responses (e.g., Alter et al., 1996; Cordova et al., 1995; Green et al., 1998). In addition, premorbid psychological disturbances, particularly a prior episode of PTSD may represent a risk factor in developing pathological stress reactions following cancer diagnosis. Individuals are also at risk of developing other anxiety and depression disorders following cancer, although individuals

with ASD may be particularly vulnerable to experiencing comorbid psychological problems, notably depression following cancer diagnosis.

We acknowledge that our findings may not generalize to other types of cancer populations. Future studies examining predictors of ASD need to focus on larger samples that include patients diagnosed with various forms of malignancies. A further shortcoming of the present study is the non-prospective design. To this end, there is a need to index the vulnerability factors that predict PTSD and longer-term psychological morbidity following cancer diagnosis. The rate of ASD (28%) in this population is higher than rates of ASD observed after motor vehicle accidents, industrial accidents, or assaults (Harvey & Bryant, 1999). This outcome may be at least partly attributable to the distinctive nature of the cancer experience. Furthermore, considering the high rates of comorbid depression in the ASD patients, the current findings point to the need for future research to understand the nature and course of posttraumatic stress in cancer populations. Understanding the factors that predispose individuals to ASD following a cancer diagnosis may enhance our understanding of the prevention and treatment of pathological trauma responses in this population.

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Table 1

Correlation Coefficients of Independent Variables and Severity of ASD (ASS)

	ASS
Age	-0.430*
Gender	0.456*
Marital status	0.136
Education	-0.059
Cancer type (Head and Neck vs. Lung)	-0.048
Cancer stage at diagnosis	0.147
Cancer treatments	0.131
Length of time since diagnosis	-0.014
Expected prognosis at diagnosis	-0.220
Attribution of Responsibility: Self-blame	0.010
Attribution of Responsibility: Others-to-blame	0.305**
Family history of cancer	0.193
Prior medical life threat	0.047
Medications – analgesics (at diagnosis)	0.210
Medications – anxiolytics/ antidepressants (at diagnosis)	0.094
Medications – sleeping tablets (at diagnosis)	0.033

Table 1 (Continued)

Correlation Coefficients of Independent Variables and Severity of ASD (ASS)

	ASS
Prior psychiatric history	0.337**
Prior anxiety history (caseness)	0.389**
Prior (non-cancer) PTSD (caseness)	0.405**
Prior depression history (caseness)	0.230*
Prior psychological therapy	0.156
Prior Alcohol Abuse Disorder (caseness)	-0.177
Prior Alcohol Dependence Disorder (caseness)	0.154
Prior Substance Dependence Disorder (caseness)	0.025
Anxiety at diagnosis (caseness)	0.385**
Depression at diagnosis (caseness)	0.500**
Alcohol Dependence at diagnosis (caseness)	0.301**
PDEQ	0.771**
PTCI – Self scale	0.516**
PTCI – World scale	0.274*
PTCI – Self-blame scale	0.085
Mini-MAC – Helplessness/hopeless	0.512**
Mini-MAC - Anxious preoccupation	0.666**
Mini-MAC - Fighting spirit	0.082
Mini-MAC - Cognitive avoidance	0.277*

Table 1 (Continued)

Correlation Coefficients of Independent Variables and Severity of ASD (ASS)

	ASS
Mini-MAC - Fatalism	0.051
BDI-II	0.691**
STAI-Y Trait scale	0.640**
STAI-Y State scale	0.595**
DUKE Social Support Scale	-0.522**
DUKE Social Support Scale	-0.522**
EORTC QLQ-C30 – QL Scale	-0.422**
EORTC QLQ-C30 – Physical Functioning	-0.186
EORTC QLQ-C30 – Role Functioning	-0.116
EORTC QLQ-C30 – Emotional Functioning	-0.677**
EORTC QLQ-C30 – Cognitive Functioning	-0.659**
EORTC QLQ-C30 – Social Functioning	-0.249*
EORTC QLQ-C30 – Fatigue Symptoms	0.359**
EORTC QLQ-C30 – Nausea and Vomiting Symptoms	0.443**
EORTC QLQ-C30 – Pain Symptoms	0.213

\*  $p < .05$ ; \*\*  $p < .01$ 

Table 2

Summary of Forward Stepwise Multiple Regression of Vulnerability and Response-Related Factors Predictive of Acute Stress Severity (ASS).

	Adjusted R <sup>2</sup>	$\beta$	SE	P
PDEQ	0.589	0.471	0.042	0.000**
EORTC QLQ-C30	0.674	-0.285	0.016	0.000**
– Cognitive Functioning				
EORTC QLQ-C30	0.706	-0.245	0.016	0.003**
– Emotional Functioning				

Note. The overall model for the multiple regression analysis of severity of ASD symptoms (total ASDI score) was statistically significant [ $F(3,78) = 65.71, p < .001$ ]; \*\*  $p < .01$

Clumsiness, more than just a slip of the hands: the significance of clumsy gestures in apraxia  
following a left hemisphere stroke.

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## Abstract

Individuals who sustain a cerebrovascular accident (CVA) in the dominant (typically left) hemisphere, are at increased risk of developing motor skill deficits due to motor-sensory impairments, as well as cognitive impairments (e.g., apraxia). Clumsiness is a central component affecting motor skills in individuals with a left hemisphere CVA (LCVA). The term "clumsiness" however, has not been adequately operationalised in the apraxia literature in clinical terms, thereby making diagnosis difficult and its contribution to apraxic disorders uncertain. Accordingly, in this study "clumsiness" was explicitly defined by establishing a set of four criteria. The non-dominant (left) hand movements of three groups of participants were examined: 10 individuals with limb-apraxia (APX); 8 individuals without limb apraxia who had sustained a LCVA (NAPX); and 19 healthy individuals without a history of brain impairment (NBD). Performance was examined on four sets of motor tasks, including a conventional praxis test (GESTURE), basic perceptual-motor co-ordination (CO-ORD) and fine movement (FINE) tasks; and a naturalistic actions test (NATURAL). A striking finding that emerged was that clumsy errors occurred frequently in all groups, including the NBD group, particularly on the praxis and fine motor tasks. In terms of quantity of clumsy errors emitted, the APX group made significantly more clumsy gestures across all four tasks in comparison to the NBD group. No differences emerged between the two clinical groups, however, in terms of total clumsy gestures emitted on the naturalistic action tasks, as well as the type of clumsy errors emitted on the fine-motor tasks. Thus, frequency and types of clumsy gestures were partly determined by task demands. These results highlight the need to consider the contribution of clumsy gestures in limb functioning following hemispheric brain damage. In broad terms, these findings highlight the importance of adopting more detailed analyses of movement errors in apraxia assessments.

*Key Words:* limb apraxia; clumsiness, stroke, brain lesion, motor functioning.

Apraxia is a disorder of the execution of skilled movements that frequently occurs as a result of left hemisphere dysfunction. A central tenet of the diagnosis of limb apraxia is that the deficit is not a result of underlying motor-sensory or cognitive deficiencies, such as weakness, incoordination, incomprehension or inattention (Geschwind, 1975). Nonetheless there is still no universally accepted taxonomy of apraxia, nor is there a standardised battery for apraxia assessment. This is at least partly due to the fact that this higher-order motor disorder may give rise to several patterns of deficits, including dissociations (Cubelli, Marchetti, Boscolo, & Della Salla, 2000; Roy et al. 2000).

The original taxonomy of limb apraxia described by Liepmann (1905/1980) identified two main varieties, ideational apraxia (IA) and motor apraxias; with motor apraxias being further subdivided into ideomotor apraxia (IMA) and limb-kinetic (also referred to as melo-kinetic) apraxia (LKA). Liepmann's taxonomy is still very much influential in apraxia assessment, particularly the dichotomy between IA and IMA. In contrast, LKA has been largely neglected within this literature, as some researchers have considered this disorder to reflect elementary motor deficits (e.g., Geschwind, 1965), although a number of investigators including Liepmann have classified LKA to be a higher-order motor disorder akin to the two classic presentations of apraxia, IA and IMA (e.g., Denes, Mantovan, Gallana, & Cappelletti, 1998; Freund, 1992; Freund & Hummelshein, 1985; Leiguarda & Marsden, 2000; Luria, 1980).

The hallmark feature of LKA is clumsy movements. Individuals classified as having LKA have often been described as eliciting coarse, awkward, fragmented, slow, poorly-timed, and "mutilated" executions of both simple and complex finger and hand movements, in both clinical and natural/domestic settings (Denes et al., 1998; Leiguarda & Marsden, 2000; Liepmann, 1905/1980). More importantly, LKA has been found to occur in the absence of elementary motor and sensory deficits, weakness, and ataxia (Denes et al., 1998).

Upon closer examination of the literature, clumsy gestures are also commonly exhibited by patients diagnosed with ideational and ideomotor apraxias (e.g., De Renzi & Lucchelli, 1988; Geschwind, 1965; Haaland & Flaherty, 1984; Heilman & Rothi, 1979; Poizner, Mack, Verfaellie, Rothi & Heilman, 1990; Poizner, Clark, Merians, Macauley, Rothi & Heilman, 1995). Consequently,

it is not uncommon for investigators to incorporate clumsy gestures as one of the error categories in apraxia assessment (De Renzi & Lucchelli, 1988; Haaland & Flaherty, 1984; McDonald, Tate & Rigby, 1994). These observations potentially contradict one of the exclusionary criteria of apraxia, namely, incoordination. Although Geschwind's (1975) frequently cited definition of apraxia implies that incoordination cannot be of such severity for it to account for the apraxia, it is clear that incoordination and apraxia may co-exist. Support for this assertion comes from Poizner and his colleagues (1990, 1995, 1997) research, whereby they examined the kinematic motions of individuals with IMA using three-dimensional computergraphic analyses. Their data indicate that individuals with apraxia show impairments in gestures and object use as a result of marked deficits in spatial orientation, coordination of joint motion, and regularity of movements, including poor fluidity due to a lack of control of movement timing.

Nevertheless, clumsiness per se, for the most part, has been overlooked or even dismissed as representing a central deficit in accounting for apractic hand functioning impairments. This oversight may be at least partly attributed to the fact that clumsy movements do not necessarily affect the actual accomplishment of the movement goal, but rather, the incidence and frequency of clumsy gestures affects the quality (or process) of obtaining the movement goal (Foundas et al., 1995). The effects of clumsy movements, therefore, may not necessarily be distinctively noticeable to either the clinician (or even the patient) amongst the other motor deficits that accompany hemispheric damage, such as hemiparesis and ataxia. In certain instances, poor motor functioning may inadvertently be attributed to these other primary motor impediments (Foundas et al., 1995). In fact Haaland and Flaherty (1984) found no differences in functioning on a standard praxis test between individuals who had sustained either right or left hemisphere brain damage, particularly in terms of the incidence of clumsy gestures (which were referred to as "partial errors" and defined as slow, non-smooth, slightly inaccurate movement related errors). They proposed that there is a need to evaluate the extent to which partial movement related errors result from clumsy and/or hypokinetic gestural impairments in individuals with hemispheric brain damage, by adopting more refined error analyses. Accordingly, in order to obtain a better understanding of the extent to which clumsiness contributes to apractic deficits, one of

the central aims of this study was to develop a more fine-grade error analyses classification system to specifically assess the prevalence and typological feature(s) of this particular gesture type.

With the exception of Poizner and his colleagues computergraphic research, the term "clumsiness", has not been adequately operationalised in the apraxia literature in clinical terms, thereby making diagnosis difficult and its contribution to apraxia uncertain. As noted, despite the fact that some researchers have included clumsiness as an error category in apraxia assessment, no authors have provided specific criteria. In particular, clumsiness has commonly been defined as a gesture implemented in an "awkward" manner (e.g., De Renzi & Lucchelli, 1988; McDonald et al., 1994; Neiman Duffy, Belanger & Coelho, 2000). There is therefore a need to develop more precise criteria for evaluating clumsy gestures within the apraxia literature, which will enable an examiner to code movements through clinical observation. Thus, the present study sought to address this issue.

In recent years there has been an increasing interest in the underpinnings of deficits in naturalistic action, defined by Schwartz and Buxbaum (1997) as "movement in the service of commonplace practical goals like food preparation and consumption" (p.269). Nonetheless, only a limited number of studies have specifically assessed the functioning of individuals with apraxia on these activities of daily living (ADL) tasks, and not surprisingly, these studies have shown that deficits in both praxis tests and basic perceptual motor tasks have been associated with poor ADL functioning (e.g., Bjerneby & Reinvang, 1985; Foundas et al., 1995; Sundet, Finset & Reinvang, 1988; Schwartz, Reed, Montgomery, Palmer, and Mayer, 1991). More recently, Neiman et al. (2000) found that clumsy gestures occurred more frequently than other movement related errors on both single and multiple object tasks within their sample of patients with left hemisphere damage. The findings from this research highlight the importance of including more ecologically valid apraxia testing measures in order to obtain a better indication of the extent to which motor functioning is compromised as a result of both the standard praxis (non-clumsy errors) as well as clumsy gestures, on both clinical tests and tasks reflecting ADL skills for individuals with hemispheric damage, with and without apraxia.

Accordingly, in light of a more refined operationalised definition of clumsiness, the present study investigated the extent to which clumsiness compared with non-clumsy errors, compromised

motor functioning in a range of hand motor tasks, including tests of basic perceptual-motor skills, praxis tasks, as well as a test of naturalistic action assessing ADL skills, for individuals with and without limb apraxia who had sustained a left hemisphere CVA, compared to a group of healthy non-brain damaged (NBD) individuals. The specific aims of our study were to:-

1. Develop a reliable and clinically useful criteria for assessing clumsy hand movements;
2. Compare the non-dominant hand functioning for individuals with and without apraxia, with a left CVA, with a group of healthy NBD individuals on a range of motor tasks, in order to:-
  - (a) Evaluate the *occurrence and type of clumsy errors* elicited; and
  - (b) Investigate the extent to which *clumsy versus non-clumsy gestures* contribute to movement impairments.

## STUDY 1

### METHOD

Study 1 was conducted in order to develop a set of criteria to define clumsy movements and determine the reliability of clinician ratings. Videos of 14 individuals who were not part of the present study, yet who had suffered a left CVA ( $n=12$ ) or closed head injury ( $n=2$ ) and had previously been diagnosed with ideomotor apraxia, were examined while they were performing transitive gestures from an apraxia battery (see Appendix A for test items). They were participants in the study described by McDonald and colleagues (1994). The patients (eight male and six female, aged an average of 70.36 years ( $SD = 15.46$ )) were undergoing inpatient rehabilitation at the time of testing.

The development of the proposed clumsy criteria occurred a priori, extracting relevant details from the empirical literature (particularly influenced by Poizner and his colleagues (1990, 1995, 1997) research on the computer-graphic kinematic analysis of apraxia gestures), as well as from the videotaped material and our own clinical observations. The criteria reflect the major components of this type of hand gesture, primarily comprising: the lack of fluidity of motion; finer elements of coarse movements, defined as fumbling motions; elements of poor spatio-temporal control contributing to the

lack of smoothness in movements; and the more overt coarse actions conventionally defined as 'clumsiness', such as spilling and dropping items (which are not directly due to weakness or inertia). Each category of error is explicitly defined so that the criteria (intended to be used collectively), can be utilised to assess the incidence of this type of gesture error in assessment contexts relying entirely on the method of clinical observation.

Four types of clumsy error categories were identified:

Type I = Poor coordination of joints, jerky movements, lacking fluidity and smoothness;

Type II = Fumbling, coarse movements;

Type III = Weak/ poor control of movement timing which included hesitancy at points of transition between movement components; (that is, once initial gesture/movement is emitted, comprises momentary pauses that contribute to the lack of fluidity in movement).

Type IV = Dropping items, losing firm grip of objects utilised, or spilling contents.

Interrater reliability of the clumsy error types was examined on a subset of participants from Study 2. Two clinician-raters separately observed the video performances of 12 participants, randomly selected from the clinical and control groups (six from each). Independent ratings were made on four motor tasks used in Study 2 (see later) that ranged in complexity, including basic perceptual-motor co-ordination (CO-ORD) and fine movement (FINE), an apraxia battery (GESTURE), and a naturalistic action test (NATURAL). The following variables were rated: total accuracy score, total number of errors, total number of clumsy errors and type of clumsy errors (I to IV).

## RESULTS

Interrater agreement was high across all scores for the CO-ORD, GESTURE and NATURAL tasks, although the reliability on the FINE accuracy and error scores was only moderate. Specifically, the correlation coefficients between raters were high for CO-ORD accuracy ( $r = 0.97$ ,  $p < 0.01$ ), total error ( $r = 0.97$ ,  $p < 0.01$ ) and clumsy error ( $r = 0.83$ ,  $p < 0.01$ ); GESTURE accuracy ( $r = 0.99$ ,  $p < 0.01$ ), total error ( $r = 0.99$ ,  $p < 0.01$ ), and clumsy error ( $r = 0.99$ ,  $p < 0.01$ ); as well as for the

NATURAL accuracy ( $r = 0.92, p < 0.01$ ), total error ( $r = 0.92, p < 0.01$ ), and clumsy error ( $r = 0.98, p < 0.01$ ). However, the reliability between raters was not statistically significant for the FINE accuracy ( $r = 0.55, p > 0.05$ ), total error ( $r = 0.54, p > 0.05$ ), and clumsy error ( $r = 0.53, p > 0.05$ ) scores, and the coefficients were low.

Interrater reliability for the four types of clumsy errors pertaining to each particular task was also examined. For both the GESTURE and NATURAL tasks a similar pattern of results were obtained. Specifically, the correlation coefficients were high for clumsy Type I [(GESTURE;  $r = 0.97, p < 0.01$ ), (NATURAL;  $r = 0.91, p < 0.01$ )], and Type III [(GESTURE;  $r = 0.94, p < 0.01$ ), (NATURAL;  $r = 1, p = 0.00$ )] errors. The reliability between raters for Type II errors was statistically significant on the NATURAL tasks ( $r = 0.70, p < 0.05$ ), although it was only moderately correlated on the GESTURE task ( $r = .61, p > 0.05$ ). A reliability coefficient could not be computed for Type IV errors, given that a ceiling effect was evident; that is, no participant made gestures that met criteria for this type of clumsy error category on either the GESTURE or NATURAL tasks. For the PMOTOR – CO-ORD task, perfect agreement was obtained for Type I and Type II clumsy errors, and a ceiling effect was evident for Type III errors. This finding may reflect the simplicity of the task demands. For the PMOTOR – FINE tasks, the correlation coefficients were high for Type II ( $r = .95, p < 0.01$ ) and Type IV ( $r = .92, p < 0.01$ ) errors, whereas reliability coefficients could not be computed for both Type I and Type III errors, given that a ceiling effect was found. On balance, these results were considered sufficiently robust to proceed with error analysis in Study 2, with the caveat that interrater reliability for FINE tasks was low.

## STUDY 2

### METHOD

#### Participants:

Two groups participated in Study 2: a clinical group with left hemisphere CVA (LCVA) and a non-brain damaged (NBD) control group. Clinical patients were recruited from two metropolitan hospitals in Sydney, Australia: Prince Henry Hospital, Little Bay and St Joseph's Hospital, Auburn.

The inclusion criteria for the clinical subjects comprised right hand dominance, evidence of pathology in the dominant hemisphere identified by computerised tomography (CT) scan that was the result of a first onset LCVA, and sufficient language comprehension to participate in testing. Language comprehension was assessed with the Oral Comprehension subtest from the Western Aphasia Battery (WAB; Kertesz, 1982). Patients were administered a brief interview focusing on medical history and were excluded if they had a history of motor disorder and/or impairments including arthritis in their hands prior to the onset of CVA, as well as a history of chronic alcohol use. No participant had a history of CVA or other neurological or motor deficits, or a history of chronic alcohol use, and all were right handed.

The samples consisted of 18 patients with de novo LCVA and 19 healthy NBD individuals. The groups were well matched in terms of gender, age and education. There were 10 males and eight females in the LCVA group, which was a similar proportion to the NBD group (eight males and 11 females) ( $\chi^2 = 0.67$ ,  $df\ 1$ ,  $p > 0.05$ ). The LCVA group was aged, on average, 63.78 years ( $SD = 13.41$ ) and the NBD group 66.11 years ( $SD = 10.54$ ) ( $t_{(35)} = 0.59$ ,  $p > 0.05$ ). Number of years of education was also comparable in the CVA and NBD groups (with means of 10.22 ( $SD = 2.56$ ) and 11.21 ( $SD = 2.92$ ) respectively) ( $t_{(35)} = 1.09$ ,  $p > 0.05$ ). Time post-onset for the LCVA participants was, on average, 25.28 months ( $SD = 59.41$ ), and all obtained the maximum score on the Oral Comprehension subtest of the WAB. Grip strength, as assessed with the Hand Dynamometer test, was examined in both groups to determine whether strength interfered with performance on motor tasks. The test was administered twice for each hand, altering hands with each trial, using the average score (force exerted in kilograms) for the non-dominant hand in statistical analysis. No significant group differences occurred ( $t_{(35)} = 0.77$ ,  $p > 0.05$ ).

## Materials

A conventional gesture production test (GESTURE) was used to classify the LCVA patients into apraxic (APX) and non-apraxic (NAPX) groups, as well as to analyse the type of errors. The test comprised 18 items, derived from other studies (see Appendix A for test items). Twelve transitive



items were those used by McDonald et al. (1994), and six intransitive items were based on items described by Haaland and Flaherty (1984) and Lehmkuhl, Poeck and Willmes (1983). Administration required the participant to elicit the gestures with each hand under three conditions: verbal command (pantomime), imitation, and (for transitive movements only) with the actual object. All participants performed each item under all three conditions, irrespective of whether they succeeded or failed on a particular condition (e.g. verbal command). Scores therefore ranged from 0–48, which comprised three sets of 12 transitive gestures and two sets of six intransitive gestures.

The classification of patients into the APX or NAPX groups occurred upon completion of data collection. The presence of apraxia was determined on the basis of the accuracy scores of the NBD group on the GESTURE test. A cut-off point less than the score of the second lowest scoring NBD participant was used to define apraxia (i.e., less than 38/48). This classification method was used, following De Renzi and colleagues (1988), because the data were not normally distributed. Ten of the 18 LCVA participants met the criteria for apraxia.

Two types of motor tasks were used: (1) perceptual-motor skill, and (2) naturalistic action. For the perceptual-motor tasks, because there were no suitably standardised screening tests of clumsiness for adults, tasks were adapted from two standardised clinical batteries for children commonly used to assess clumsiness and motor impairments: the Bruininks-Oseretsky Test of Motor Proficiency (BOTMP; Bruininks, 1978), and the Movement Assessment Battery for Children (Movement ABC; Henderson & Sugden, 1992). The tasks examined coordination (CO-ORD) and fine motor movement (FINE). The CO-ORD items comprised (i) touching the nose with index finger with eyes closed for four consecutive trials (score range 0-4) (BOTMP, subtest 5, item 7); (ii) thumb touching each finger in sequence with eyes closed for two repetitions (score range 0-8) (BOTMP; subtest 5, item 8); and (iii) a dysdiadochokinesia task (rapid alternating hand movement) with eyes opened for 5 repetitions (score range 0-5). The FINE items consisted of two subtests from the Movement ABC: (i) the Turning Peg Test in which 12 consecutive pegs on a peg board are turned (score range 0-12); and (ii) the Placing Coins in Box Test in which 16 plastic coins are inserted into a box through a slot (score range 0-16).

The CO-ORD and FINE tasks were scored in accordance with modified criteria, adapted from the standard scoring method as described in the manuals, to include the clumsy error criteria developed in Study 1. Specifically, for CO-ORD tasks (i) and (ii), clumsy error Types I and II were examined, and for CO-ORD task (iii), clumsy error Types I, II, and III were examined. For the two FINE tasks, all four clumsy error types were assessed.

A test of naturalistic action (NATURAL) was also administered in order to evaluate the participants' abilities to perform functional, naturalistic actions with a multiple-objects test. This test was adapted from the items described by Buxbaum, Schwartz, Coslett and Carew (1995), and comprised three tasks: (i) preparing a letter for mailing; (ii) making a single slice of toast with butter and jam; and (iii) preparing a cup of instant coffee with two teaspoons of sugar and milk. Videotapes of the responses were analysed for accuracy, and presence and type of movement and sequencing errors, based on the taxonomy described by Buxbaum et al. (1995). In addition, presence and type of clumsy errors were analysed, according to the criteria developed from Study 1. Nine non-clumsy error categories were developed, which are described in Appendix B. Analyses of errors were evaluated as a function of the number of sub-components per task. In particular, tasks (i) and (ii) comprised three components each, and task (iii) consisted of five components. Accuracy scores thus ranged from 0-11, however there was no maximum limit for error scores as participants could manifest more than one type of error per item.

#### **Procedure:**

Participants were assessed individually in a quiet room (either at the hospitals, or in their own homes) and they were seated at a table with the examiner sitting opposite them. Testing time was approximately 2.5 hours, conducted over one or two sessions. After signing the consent form, the tests were administered in a fixed order: GESTURE, NATURAL, CO-ORD, and FINE. Participants were tested separately for each hand on all tasks, with statistical analyses using the data from the non-dominant (left) hand, ipsilateral to the lesion. Each participant's performances on all tests were videotaped in order to score accuracy of movement and type of errors.

## RESULTS

### Statistical analyses

Error scores were used for statistical analyses and included frequency (occurrence of at least one error per variable) and quantity of clumsy and non-clumsy errors, as well as types of clumsy error (Types I – IV). Initial screening of the data revealed, as expected, that many variables were not normally distributed. Accordingly, Kruskal-Wallis one-way analyses of variance and post-hoc Mann-Whitney U and Wilcoxon tests were used to analyse the group data. Chi-square analyses were also used to analyse the proportion of participants who elicited each type of clumsy error for all relevant tasks. Bonferroni adjustments were made to each set of tests in order to control for an inflated Type 1 error rate due to multiple comparisons. Specifically, both clumsy and non-clumsy error scores were elicited on all four tasks (GESTURE, CO-ORD, FINE and NATURAL), and the critical alpha was set at  $p < .01$ . Analysis of type of clumsy error used 15 comparisons from the four relevant tasks (i.e., all four clumsy error types were possible on each of the GESTURE, FINE, and NATURAL tasks, but only three of the four clumsy errors were possible on the CO-ORD task), and hence the critical alpha was set at  $p < .003$ . Analysis of type of non-clumsy error was only applicable for two tasks (GESTURE and NATURAL), and each of these tasks had a distinct set of non-clumsy error categories. Specifically, the GESTURE task comprised seven types of non-clumsy errors (which are also presented in Appendix A), and thus the critical alpha was set at  $p < .007$ . The NATURAL task comprised nine types of non-clumsy errors (presented in Appendix B), and the critical alpha was set at  $p < .006$ .

### Occurrence and Number of Clumsy Errors:

Frequency data, regarding the presence and type of clumsy errors, are presented in Table 1, but the focus of the results is on mean scores for the number of clumsy errors, which are presented in Table 2. An overall group difference was found on the GESTURE task in terms of the number of clumsy errors elicited ( $\chi^2 = 17.82$ ,  $p < .01$ ) (see Table 2). Not surprisingly, given that GESTURE was

used as the classifying variable, the APX group made significantly more clumsy errors than the NBD group ( $z = -3.78, p < .01$ ). There was also a significant difference in clumsy error scores between the APX and NAPX ( $z = -3.00, p < .05$ ) groups.

Insert Tables 1 and 2 about here

An overall group difference was found on the CO-ORD tasks in terms of number of errors elicited ( $\chi^2 = 11.90, p < .05$ ), with the APX group making significantly more clumsy errors than the NBD ( $z = -3.20, p < .01$ ) group. Significant group differences were found on the FINE tasks ( $\chi^2 = 10.92, p < .05$ ). Specifically, the APX group made significantly more clumsy errors than both the NBD ( $z = -3.02, p < .05$ ) and the NAPX ( $z = -2.73, p < .05$ ) groups.

An overall significant group difference was also found in terms of number of clumsy errors elicited on the NATURAL task ( $\chi^2 = 20.14, p < .01$ ) with the APX group making significantly more clumsy errors than the NBD group ( $z = -4.30, p < .01$ ).

#### **Type of Clumsy Errors – Occurrence and Number:**

Descriptive data for the occurrence and number of clumsy error types are also presented in Tables 1 and 2 respectively. In terms of the number of errors elicited on the GESTURE task (Table 2), an overall group difference for Type I (jerky, non-fluid movement) clumsy errors was very close to significance ( $\chi^2 = 11.84, p = .05$ ). Post-hoc analyses however, indicated that the only difference occurred for Type I clumsy errors, with the APX group making significantly more errors compared to the NBD group ( $z = -3.01, p < .05$ ). There were no significant group differences, however, for either the CO-ORD tasks for any of the three applicable clumsy errors (Types I, II, and III), nor the FINE tasks for any of the four clumsy error types.

In terms of number of errors made on the NATURAL tasks (Table 2), an overall significant group difference for Type I clumsy errors was found ( $\chi^2 = 12.29, p < .05$ ). Interestingly, post-hoc analyses indicated no significant differences between the specific groups, although there was a strong trend towards significance between both the APX and NAPX groups ( $z = -2.79, p = .005$ ), as well as

between the APX and NBD groups ( $z = -2.96$ ,  $p = .003$ ). A significant difference was also found for the number of Type II (fumbling, coarse movement) clumsy errors ( $\chi^2 = 17.44$ ,  $p < .01$ ), with the APX group making considerably more errors than the NBD group ( $z = -3.86$ ,  $p < .05$ ). There was also a strong trend towards significance for the number of clumsy Type II error scores between the NBD and NAPX groups ( $z = -3.38$ ,  $p = .005$ ).

### **Non-Clumsy Errors – Occurrence and Number:**

The presence and number of non-clumsy errors, and results of analyses for non-clumsy error scores appear in Tables 3 and 4 respectively. In terms of the total number of non-clumsy errors elicited on the GESTURE task (Table 4), the APX group made substantially more errors than the NBD group ( $Z = -3.05$ ,  $p < .01$ ). By contrast, no significant group differences emerged in relation to the number of non-clumsy errors emitted on the perceptual motor (CO-ORD and FINE) tasks (Table 4).

All participants in both clinical groups and the majority (89.5%) of participants in the NBD group made at least one non-clumsy error on the NATURAL task. Significant group differences were found in terms of the number of non-clumsy errors elicited on this task ( $\chi^2 = 11.13$ ,  $p < .01$ ) (Table 4), with, the APX group making more errors than the NBD group ( $Z = -3.15$ ,  $p < .05$ ).

**Insert Tables 3 and 4 about here**

### **Types of Non-Clumsy Errors – Presence and Number:**

Descriptive data for the presence and number of non-clumsy error types are also presented in Tables 3 and 4 respectively. On the GESTURE task, an overall group difference in the incidence of 'Body-Part-As-Object' (BPO) errors was very close to significance ( $\chi^2 = 9.37$ ,  $p = .009$ ). Post-hoc analyses however, indicated that the APX group made significantly more BPO errors than the NBD group ( $Z = -2.78$ ,  $p < .05$ ), although no group differences were found between the LCVA groups, nor between the NAPX and NBD groups. The most frequent type of non-clumsy error made on the GESTURE test in the three groups was Spatial errors, followed by BPO (see Table 3). The least

frequently occurring errors were Perseverations and Augmentations. Specifically, no participant was found to make any Perseverative errors, whilst no participant in either the APX and NBD groups made any Augmentations. In addition, no individual in either the NAPX and NBD groups made Unsustainable Action errors. Interestingly, on the GESTURE task, all participants from each of the groups made more clumsy errors than any specific non-clumsy error type.

On the NATURAL task, an overall group difference was found for the number of Spatial Misalignment errors elicited ( $\chi^2 = 10.95$ ,  $p < .05$ ), with the APX group making significantly more errors than the NBD group ( $Z = -3.18$ ,  $p < .05$ ). On this task, the most frequent non-clumsy error type elicited by the APX group was Spatial Misalignment errors (90%), followed by Sequencing errors (80%). The reverse pattern of results were obtained for the non-apractic groups; that is, the most common error type was Sequencing (75% for the NAPX group, and 78.9% for the NBD group), followed by Spatial Misalignment error (62.5% for the NAPX group, and 26.3% for the NBD group). The least frequent errors emitted by each of the three groups were Substitution and Incorrect Content Gesture errors. Specifically, no participant made any Substitution errors, and no individual from the two non-apractic groups made any Incorrect Content Gesture errors. In addition, the frequency for both clumsy and non-clumsy errors elicited by the APX group were comparable, whereby all participants made at least one type of clumsy and non-clumsy error on the NATURAL tasks. In contrast, the frequency of non-clumsy errors occurred more often than clumsy gestures in both the NAPX and NBD groups.

#### **Relationship among clumsy and non-clumsy errors and motor tasks:**

Spearman rank-order correlations between clumsy and non-clumsy errors on the grip and four sets of motor tasks for the two clinical (LCVA) groups are presented in Table 5. Importantly, grip (left) hand strength was significantly correlated with clumsy errors on both the GESTURE ( $r = -0.48$ ,  $p < .05$ ) and NATURAL ( $r = -0.57$ ,  $p < .05$ ) tasks. Clumsy errors on the GESTURE task were also found to be significantly correlated with clumsy errors on the NATURAL task ( $r = 0.67$ ,  $p < .01$ ). In addition, both clumsy errors on the NATURAL tasks ( $r = 0.50$ ,  $p < .05$ ), and non-clumsy errors on the

CO-ORD tests ( $r = 0.49$ ,  $p < .05$ ) were significantly related with clumsy gestures on the FINE motor tests. Non-clumsy errors on the GESTURE task were also significantly associated with clumsy gestures on the CO-ORD tasks ( $r = 0.51$ ,  $p < .05$ ).

Insert Table 5 about here

## DISCUSSION

One of the aims of this research was to develop a set of criteria in order to assess the frequency and quantity of clumsy gestures as part of the standard apraxia assessment. A set of four specific criteria were developed which could be used collectively to examine the incidence of clumsy gestures via clinical observation. The reliability of the criteria was evaluated on the basis of four motor tasks ranging in complexity, and inter-rater agreement for total clumsy gestures was found to be very high on three tests (a primary motor coordination task (CO-ORD), a standard apraxia test (GESTURE), and a test of naturalistic actions (NATURAL)). In addition, inter-rater agreement for the four specific clumsy error categories (Types I, II, III, and IV) were generally found to be high across the four motor tasks.

A striking finding of this study was that a high proportion of the NBD group made at least one clumsy error on the fine movement task (100%) and a standard apraxia test (84.2%). One-third of the group also made clumsy errors on the naturalistic action task. Even on a test of coordination, almost 16% of the group made at least one clumsy error. The errors were not confined to clumsy errors, however, and the occurrence of non-clumsy errors was also common in this group on NATURAL (89.5%), and more than half also made at least one non-clumsy error on GESTURE. By contrast, occurrence of non-clumsy errors on basic motor tasks in the NBD group was low, both for FINE (5.3%) and CO-ORD (5.3%). These findings highlight the necessity of having normative data on error types for the clinical diagnosis of apraxia because occurrence of errors on a range of motor tasks, including standard praxis tests, cannot be considered pathognomonic of apraxia. Although the issue of errors made by non-brain damaged individuals has previously been noted (e.g., Neiman et al., 2000), no comprehensive normative data have appeared to date.

Clumsy errors occurred commonly in the two clinical groups, as well as the NBD group. They occurred most frequently on the GESTURE and FINE tasks, more so for the patients diagnosed with apraxia in comparison with both the nonapraxic and NBD groups. The most commonly occurring clumsy errors were Type I (jerky, nonfluid movement) on the GESTURE task, with the APX group making significantly more errors than the NBD group. Although less common, the Type II clumsy errors (fumbling, coarse movements) on the NATURAL tasks were more common in both clinical groups in comparison with the NBD group. The least frequently occurring clumsy errors in each clinical group were Type III (poor control of movement timing) and Type IV (dropping, spilling or losing grip). Even so, it is relevant to note that there was some variation in frequency of type of clumsy error and task demands. Type I errors most commonly occurred on GESTURE and CO-ORD, whereas Type IV occurred most frequently on FINE; and for the clinical groups, Types I and II on NATURAL. This pattern of findings may be attributed to the fact that 3 of the tasks are made up of discrete movements, which enhances the prospect of eliciting Type I clumsy errors, whereas the NATURAL task has many movement components comprising each item, which increases the probability of exhibiting Type II clumsy errors. It also seems of interest that Type IV errors occurred commonly on FINE, but never on the NATURAL tasks. Using the data from the two clinical groups, intercorrelations among clumsy errors on the four tasks reached statistical significance for two comparisons ( $r_s = 0.67$  between GESTURE and NATURAL and  $r_s = 0.50$  between FINE and NATURAL), suggesting that although there is shared variance between tasks, there was sufficient unaccounted variance to indicate that clumsiness on one task was not totally explained by clumsiness on another task.

A potentially important finding was the significant correlation coefficients between hand weakness and clumsy errors on the GESTURE ( $r_s = -0.48$ ) and NATURAL ( $r_s = -0.57$ ) tasks, suggesting that hand weakness contributes to clumsy errors. Post-hoc comparisons showed that the APX group had significantly weaker grip strength (using their ipsilateral/left hand) than the NAPX group ( $t_{(16)} = -3.10$ ,  $p < 0.05$ ). Although hand weakness could have at least partly contributed to the higher prevalence of clumsy errors on the NATURAL tasks within the APX group, nonetheless their



performance was not significantly different to the NAPX group. Clearly, however, this finding necessitates the replication of this design in future research in order to ascertain whether the same findings emerge between LCVA individuals, with and without apraxia, who are assessed to have comparable hand strength. Taken together, these results suggest that the incidence of clumsy errors at least partly contributes to motor production deficits on both primary fine motor and standard praxis tests for individuals with apraxia, compared with nonapraxic and non-brain damaged individuals.

Despite the fact that to our knowledge, no other published study to date has specifically examined the contribution of clumsy gestures to apraxic deficits in individuals who have sustained left hemisphere damage (LHD), the results from our research concur with several studies within the literature. In particular, Neiman et al. (2000) reported that within their sample of aphasic participants with LHD, clumsy errors (defined as “awkward” gestures), contributed the most to poor quality of motor functioning using both single and multiple objects in tasks assessing ADL skills. Interestingly, their samples’ performance on single object tasks was significantly worse than their performance on multiple object tasks. Similarly, within our study, the APX group made significantly more clumsy errors than the NAPX group on the two tests that entailed single object use (i.e, GESTURE and FINE tasks), whilst no group differences arose on tasks involving multiple objects (i.e, NATURAL test). Neiman and colleagues accounted for this discrepancy in motor functioning between single object and multiple object test paradigm, by proposing that performance on multiple object tasks is enhanced by the mere presence of related objects which provide additional movement cues to aid performance functioning in accomplishing the movement goal. De Renzi and Lucchelli (1988) had previously postulated that poor performance on multiple object test paradigms (akin to the NATURAL test) reflect neurocognitive deficits in motor *concept* formation, whereas poor functioning on single object test paradigms (akin to the GESTURE test) is indicative of motor *production* deficits. This assertion once again emphasises that the motor deficits evident within the APX group in the present study reflects impairments in the execution of movements, rather than reflecting a dysfunction in the conceptual formation of the movement goal.

The results from the present study also correspond with an increasingly consistent pattern of findings which is emerging within the recent apraxia literature, indicating that apraxic functioning following LHD seems to be a significant predictor of poor motor functioning on a range of tests including fine motor skills and more ecologically applicable tasks reflecting ADL functioning. In particular, Bell et al. (1976) (in Bjorneby & Reinvang, 1985) found that kinetic apraxia (defined as loss of fine movements in the ipsilateral hand), predicted poorer performance in ADL tasks within a sample of patients with LHD. Similarly, Bjorneby and Reinvang (1985) and in a related study, Sundet et al. (1988) noted within their sample of right hemiplegic patients, poor performance on tests of fine motor skills (specifically, the grooved peg test from the Halstead battery) and copy ability using the ipsilateral hand were strong predictors of poor ADL functioning. These findings are comparable to our results in which the inter-correlations between clumsy errors for the two clinical groups reached statistical significance between GESTURE and NATURAL ( $r=0.67$ ) and FINE and NATURAL ( $r=0.50$ ). It is important to highlight that the central findings stemming from this present research do not explicitly pertain to any particular type of apraxia disorder, as the overarching aim was to examine the prevalence and extent to which clumsiness, compared with non-clumsy gestures, compromise motor functioning in apraxia in general. The next step in future research will be to ascertain the extent to which clumsiness is a prevalent feature within the different subtypes associated with this cognitive motor deficit, as well as evaluate the extent to which this type of gestural impairment hinders progress in rehabilitation, particularly with ADL skills. Nonetheless, our findings lend support to the group of researchers who have not discounted limb-kinetic apraxia as merely the result of basic, elemental motor deficits, but instead have considered it to be a higher cognitive disorder akin to the two classical forms of apraxia, IA and IMA (e.g. Denes et al., 1988; Leigurada & Marsden, 2000).

In recent times, a number of researchers have highlighted the need to develop more detailed analyses of movement errors in the apraxia assessment which reflect both conceptual (process) and production (execution) motor functioning, in order to obtain a better understanding of the underlying mechanisms and processes of this disorder (e.g., Roy et al., 2000). Accordingly, the present study has shown that by adopting a finer-grade analysis of clumsy gestures, clumsiness has been found to be a

contributing factor to the motor impairments associated with apraxia in accomplishing an action goal, particularly on conventional gesture and elemental motor tasks compared to non-apractic individuals with brain damage. Thus, from an assessment perspective, clumsiness may have been overlooked within the apraxia literature due to the continuing problems inherent with the numerous and sometimes ill-defined classification and scoring systems utilised by various researchers (Haaland & Flaherty, 1984; Roy et al., 2000; Tate & McDonald, 1995). There is therefore an increasing need, to evaluate, refine, and eventually standardise the various apraxia classification and scoring taxonomies in order to resolve the discrepancies inherent within this specialised field of neuropsychology (Roy et al., 1990). This goal can be more effectively accomplished by incorporating a more comprehensive assessment battery (aside from relying on the conventional praxis tests), to include more ecologically valid tasks such as ADL skills (Cubelli et al., 2000; van Heugten et al., 1999). This will enable a better understanding of the complexity of this cognitive motor disorder, considering that akin to other types of neuropsychological deficits, executive motor impairments occur on a continuum (Mayer, Reed, Schwartz, Montgomery, & Palmer, 1990). Essentially, this should prove invaluable in assisting with the diagnosis and subsequent rehabilitation needs of apraxic individuals.

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## APPENDIX A:

### Items Used in the GESTURE task

#### *Transitive Items and Movements Requested:*

- |                                 |  |
|---------------------------------|--|
| 1. Comb:                        | Comb hair                                |
| 2. Toothbrush:                  | Brush teeth                              |
| 3. Cup:                         | Drink from cup                           |
| 4. Key:                         | Unlock door                              |
| 5. Scissors:                    | Cut paper                                |
| 6. Hammer:                      | Hammer in a nail                         |
| 7. Pen:                         | Write name                               |
| 8. Coin:                        | Flip a coin                              |
| 9. Spoon:                       | Stir coffee with spoon                   |
| 10. Fan:                        | Fan oneself with handheld paper-fan.     |
| 11. Pistol (small plastic toy): | Shoot with a pistol                      |
| 12. Screwdriver:                | Use a screwdriver on a screw in the wall |

#### *Intransitive Movements:*

13. Wave goodbye
14. Salute
15. Scratch head
16. Beckon come here
17. Stop signal
18. Make a fist

#### *Error Categories (Non-Clumsy):*

1. Spatial Orientation
2. Unsustained Action
3. Body-Part as – Object (BPO)
4. Substitution
5. Amorphous
6. Perseveration

7. Augmentation

## APPENDIX B

## Naturalistic Action Tasks (NATURAL) – Summary of non-clumsy error categories

- Non-clumsy error type 1: Substitution of object or location. E.g. stir coffee with knife (*object substitution*), or place coffee in sugar bowl (*location substitution*).
- Non-clumsy error type 2: Incorrect gesture for content (i.e. correct object used with incorrect gesture). E.g., stirred milk, but did not pour into cup.
- Non-clumsy error type 3: Incorrect gesture for motor and spatial component (i.e., problem with grasp or gesture orientation). E.g., grasped spoon like an ice-pick and used with stabbing motions.
- Non-clumsy error type 4: Spatial misalignment of objects. E.g., letter folded too large to fit into envelope.
- Non-clumsy error type 5: Tool/ implement omission. E.g., Poured sugar directly from bowl into cup, without using teaspoon.
- Non-clumsy error type 6: Subtask omission. E.g., Fail to butter bread, only use jam.
- Non-clumsy error type 7: Sequence error, including action omissions (e.g., seal envelope without placing letter inside), action perseverations (e.g., butter bread, place jam on bread, and then re-butter bread), and action anticipation (e.g., stir contents of cup after each ingredient added: coffee – stir – sugar – stir – water – stir – milk – stir).
- Non-clumsy error type 8: Action addition or substitution (i.e., action not part of steps involved in completing task), includes anomalous actions. E.g, place stamp on letter, inside envelope.
- Non-clumsy error type 9: Quality error, comprises inappropriate or inexact quantity (spatial or volume). E.g., Overflow cup with water.



Table 1: Proportion of participants for each group who elicited (at least one) clumsy errors for each task, and results of Chi-Square Analyses using Fisher's Exact score

	NBD (n=19)	NAPX (n=8)	APX (n=10)	Chi-Square ( $\chi^2$ )	p	Post-hoc ( $\chi^2$ )	p
<b><u>GESTURE</u></b>							
Type I	84.2	87.5	100	1.57	ns		
Type II	73.7	87.5	90.0	1.17	ns		
Type III	15.8	25.0	60.0	5.76	ns		
Type IV	36.8	37.5	70.0	3.09	ns		
	0	0	10.0	2.50	ns		
<b><u>PMOTOR:</u></b>							
(i) COORD							
	15.8	25.0	77.8	10.01	0.004*	APX-NAPX: 1.02 NBD-NAPX: 0.32 APX - NBD: 10.22	ns ns 0.003*
Type I	15.8	25.0	66.7	6.94	ns		
Type II	5.3	0	44.4	7.05	ns		
Type III	0	0	0	-	-		

+ p = .05; \* p &lt; .05; \*\* p &lt; .01

Table 1 (Continued): Proportion of participants for each group who elicited (at least one) clumsy errors for each task, and results of Chi-Square Analyses using Fisher's Exact score

	NBD (n=19)	NAPX (n=8)	APX (n=10)	Chi-Square ( $\chi^2$ )	p	Post-Hoc ( $\chi^2$ )	p
<b><u>PMOTOR:</u></b> <b>(ii) FINE</b>							
Type I	100	100	100	-	-		
Type II	0	0	22.2	4.31	ns		
Type III	10.5	50.0	44.4	6.15	ns		
Type IV	31.6	12.5	33.3	1.17	ns		
	94.7	87.5	100	1.43	ns		
<b><u>NATURAL</u></b>							
Type I	31.6	75.0	100	14.29	0.001**	APX - NAPX: 2.81 NBD - NAPX: 4.30 APX - NBD: 12.40	ns ns .000**
Type II	26.3	12.5	80.0	10.07	ns (0.006)	APX - NAPX: 8.10 NBD - NAPX: 0.62 APX - NBD: 7.64	ns (.015) ns ns
	10.5	75.0	80.0	17.41	0.000**	APX - NAPX: .06 NBD - NAPX: 11.22 APX - NBD: 14.00	ns .002* .000**

+ p = .05; \* p < .05; \*\* p < .01

Table 1 (Continued): Proportion of participants for each group who elicited (at least one) **clumsy errors** for each task, and results of Chi-Square Analyses using Fisher's Exact score

	NBD (n=19)	NAPX (n=8)	APX (n=10)	Chi-Square ( $\chi^2$ )	p	Post-Hoc ( $\chi^2$ )	p
<b><u>NATURAL</u></b> (Continued)							
Type III	10.5	0	30.0	3.01	ns		
Type IV	5.3	37.5	60.0	10.56	ns (0.004)	APX – NAPX: 0.90 NBD – NAPX: 4.64 APX – NBD: 10.72	ns ns .003+

+ p = .05; \* p < .05; \*\* p < .01

Table 2: Means (and standard deviations) of clumsy errors for each group, quantity of error types, and results of Kruskal-Wallis One-Way ANOVAs and post-hoc (Mann-Whitney U) tests

	NBD (n=19)	NAPX (n=8)	APX (n=10)	Kruskal Wallis ( $\chi^2$ )	p	Mann Whitney (z)	p
<b><u>GESTURE</u></b>							
Type I	2.53 (3.01)	4.00 (2.39)	9.20 (3.16)	17.82	0.000**	APX-NAPX: -3.00 NBD-NAPX: -1.60 APX - NBD: -3.78	0.003* ns 0.000**
Type II	1.84 (2.65)	2.63 (1.77)	6.40 (3.10)	11.84	0.003+	APX -NAPX: -.268 NBD - NAPX: -1.56 APX - NBD: -3.01	ns ns 0.002*
Type III	0.21 (0.54)	0.88 (1.64)	1.50 (1.65)	6.61	ns		
Type IV	0.47 (0.70)	0.50 (0.76)	1.20 (1.32)	3.20	ns		
	0	0	0.10 (0.32)	2.70	ns		
<b><u>PMOTOR:</u></b>							
(i) COORD							
Type I	0.32 (0.95)	0.25 (0.46)	2.56 (3.21)	11.90	0.003*	APX-NAPX: -2.37 NBD-NAPX: -0.47 APX - NBD: -3.20	ns ns 0.001**
Type II	0.26 (0.73)	0.25 (0.46)	1.56 (2.51)	7.58	ns		
Type III	0.01 (0.23)	0	1.0 (1.94)	9.38	ns		
	0	0	0	0	ns		

+ p = .05; \* p &lt; .05; \*\* p &lt; .01

Table 2 (Continued) : Means (and standard deviations) of **clumsy errors** for each group, quantity of error types, and results of Kruskal-Wallis One-Way ANOVAs and post-hoc (Mann-Whitney U) tests

	NBD (n=19)	NAPX (n=8)	APX (n=10)	Kruskal Wallis ( $\chi^2$ )	p	Mann Whitney (z)	p
<b><u>PMOTOR:</u></b> <b>(ii) FINE</b>							
Type I	3.00 (1.89)	2.50 (1.20)	8.33 (6.52)	10.92	0.004*	APX-NAPX: -2.73 NBD-NAPX: -0.33 APX - NBD: -3.02	0.006* ns 0.003*
Type II	0	0	1.11 (2.98)	6.17	ns		
Type III	0.11 (0.32)	0.63 (0.74)	1.78 (3.03)	6.45	ns		
Type IV	0.47 (0.84)	0.13 (0.35)	0.78 (1.39)	1.43	ns		
	2.42 (1.54)	1.75 (1.16)	4.67 (2.96)	8.02	ns		
<b><u>NATURAL</u></b>							
Type I	0.58 (0.96)	1.75 (1.58)	3.80 (1.32)	20.14	0.000**	APX - NAPX: -2.44 NBD - NAPX: -2.11 APX - NBD: -4.30	ns ns 0.000**
Type II	0.32 (0.58)	0.13 (0.35)	1.40 (1.07)	12.29	0.002*	APX - NAPX: -2.79 NBD - NAPX: -0.81 APX - NBD: -2.96	ns (0.005) ns .003+
	0.11 (0.32)	1.13 (0.99)	1.40 (0.97)	17.44	0.000**	APX - NAPX: -0.70 NBD - NAPX: -3.38 APX - NBD: -3.86	ns ns (0.005) 0.001*

+ p = .05; \* p &lt; .05; \*\* p &lt; .01

Table 2 (Continued) : Means (and standard deviations) of clumsy errors for each group, quantity of error types, and results of Kruskal-Wallis One-Way ANOVAs and post-hoc (Mann-Whitney U) tests

	NBD (n=19)	NAPX (n=8)	APX (n=10)	Kruskal Wallis ( $\chi^2$ )	p	Mann Whitney (z)	p
<b><u>NATURAL</u></b> (Continued)							
Type III	0.11 (0.32)	0	0.30 (0.48)	3.62	ns		
Type IV	0.01 (0.23)	0.50 (0.76)	0.70 (0.67)	10.14	ns		

+ p = .05; \* p &lt; .05; \*\* p &lt; .01

Table 3: Proportion of participants for each group who elicited (at least one) non-clumsy errors for each task, and results of Chi-Square Analyses using Fisher's Exact score

	NBD (n=19)	NAPX (n=8)	APX (n=10)	Chi-Square ( $\chi^2$ )	p	Post-hoc ( $\chi^2$ )	p
<b>GESTURE</b>	52.6	62.5	90	4.03	ns		
NC I (Spatial)	52.6	62.5	80	2.04	ns		
NC II (Unsust. Act)	0	0	20	3.95	ns		
NC III (BPO)	21.1	25	70	6.79	ns		
NC IV (Subst)	5.3	12.5	20	1.82	ns		
NC V (NR)	0	12.5	10	2.79	ns		
NC VI (Persev)	0	0	0	-	ns		
NC VII (Augment)	0	12.5	0	2.95	ns		
<b>PMOTOR:</b>							
(i) COORD	5.3	12.5	33.3	3.70	ns		
(ii) FINE	5.3	0	11.1	1.19	ns		

+ p = .05; \* p &lt; .05; \*\* p &lt; .01

Table 3 (Continued): Proportion of participants for each group who elicited (at least one) **non-clumsy errors** for each task, and results of Chi-Square Analyses using Fisher's Exact score

	NBD (n=19)	NAPX (n=8)	APX (n=10)	Chi-Square ( $\chi^2$ )	p	Post-hoc ( $\chi^2$ )	p
<b>NATURAL</b>	89.5	100	100	1.28	ns		
E 1 (Subst)	0	0	0	-	ns		
E 2 (Content)	0	0	10	2.50	ns		
E 3 (Spatial)	26.3	12.5	30	0.82	ns		
E 4 (Sptl Misalign)	26.3	62.5	90	11.20	.003*	APX-NAPX: 1.95 NBD-NAPX: 3.16 APX - NBD: 10.64	ns ns 0.002*
E 5 (Tool Omission)	10.5	50	10	5.27	ns		
E 6 (Subtask Omis.)	21.1	50	50	3.47	ns		
E 7 (Sequ Error)	78.9	75	80	0.29	ns		
E 8 (Add/subtr)	5.3	12.5	20	1.82	ns		
E 9 (Quantity)	15.8	25	40	2.16	ns		

+ p = .05; \* p &lt; .05; \*\* p &lt; .01



Table 4: Means (and standard deviations) of each group for non-clumsy error scores, quantity of error types, and results of Kruskal-Wallis One-Way ANOVAs and post-hoc (Mann-Whitney U) tests

	NBD (n=19)	NAPX (n=8)	APX (n=10)	Kruskal Wallis ( $\chi^2$ )	P	Mann Whitney (z)	p
<b><u>GESTURE</u></b>	2.26 (3.18)	3.25 (3.58)	6.80 (3.43)	9.85	0.007*	APX-NAPX: -2.01 NBD-NAPX: -0.81 APX-NBD: -3.05	ns ns 0.002*
NC I (Spatial)	1.68 (2.40)	2.25 (2.05)	3.50 (2.88)	3.75	ns	-	
NC II (Unsust. Act)	0	0	0.80 (1.93)	5.56	ns	-	
NC III (BPO)	0.47 (1.07)	0.38 (0.74)	2.20 (1.75)	9.37	ns	-	
NC IV (Subst)	0.11 (0.46)	0.13 (0.35)	0.20 (0.42)	1.27	ns	-	
NC V (NR)	0	0.13 (0.35)	0.01 (0.32)	2.22	ns	-	
NC VI (Persev)	0	0	0	0	ns	-	
NC VII (Augment)	0	0.38 (1.06)	0	3.63	ns	-	

+ p = .05; \* p &lt; .05; \*\* p &lt; .01

Table 4: (Continued) Means (and standard deviations) of each group for non-clumsy error scores, quantity of error types, and results of Kruskal-Wallis One-Way ANOVAs and post-hoc (Mann-Whitney U) tests

	NBD (n=19)	NAPX (n=8)	APX (n=10)	Kruskal Wallis ( $\chi^2$ )	P	Mann Whitney (z)	p
<b>PMOTOR:</b>							
(i) COORD	0.11 (0.46)	0.50 (1.41)	0.67 (1.32)	3.64	ns	-	-
(ii) FINE	0.11 (0.46)	0	0.33 (1.00)	1.04	ns	-	-
<b>NATURAL</b>	2.42 (1.64)	4.13 (2.17)	5.80 (3.05)	11.13	0.004**	APX-NAPX: -0.99 NBD-NAPX: -2.02 APX-NBD: -3.15	ns ns 0.002*
E 1 (Subst)	0	0	0	0	ns	-	-
E 2 (Content)	0	0	0.10 (0.32)	2.70	ns	-	-
E 3 (Spatial)	0.26 (0.45)	0.25 (0.71)	0.50 (0.85)	0.74	ns	-	-
E 4 (Sptl Misalign)	0.53 (1.02)	1.0 (1.07)	2.40 (1.84)	10.95	0.004*	APX-NAPX: -1.83 NBD-NAPX: -1.75 APX-NBD: -3.18	ns ns 0.001*
E 5 (Tool Omission)	0.11 (0.32)	0.63 (.74)	0.10 (0.32)	6.63	ns		
E 6 (Subtask Omis.)	0.26 (0.56)	0.63 (.74)	0.50 (0.53)	2.95	ns		

+ p = .05; \* p &lt; .05; \*\* p &lt; .01

Table 4: (Continued) Means (and standard deviations) of each group for **non-clumsy error scores**, quantity of error types, and results of Kruskal-Wallis One-Way ANOVAs and post-hoc (Mann-Whitney U) tests

	NBD (n=19)	NAPX (n=8)	APX (n=10)	Kruskal Wallis ( $\chi^2$ )	P	Mann Whitney (z)	p
<b><u>NATURAL</u></b>							
<b>(Continued)</b>							
E 7 (Sequ error)	1.05 (0.71)	1.25 (1.04)	1.20 (1.14)	0.16	ns		
E8 (Add/Subs)	0.01 (0.23)	0.13 (0.35)	0.30 (0.67)	1.59	ns		
E9 (Quantity)	0.16 (0.37)	0.25 (0.46)	0.70 (1.06)	2.64	ns		

+ p = .05; \* p < .05; \*\* p < .01

Table 5: Spearman rank-order correlations for clumsy and non-clumsy errors among motor tasks between APX and NAPX, LCVA groups.

	1	2 (a)	2 (b)	3 (a)	3 (b)	4 (a)	4 (b)	5 (a)	5 (b)
1. GRIP	-								
2 (a) GESTURE Clumsy errors		-.48*	.02	-.57*	.25	-.34	.14	-.29	.21
2 (b) GESTURE Non-clumsy		-	.29	.67**	.29	.36	.04	.38	.06
3 (a) NATURAL Clumsy			-	.33	.38	.51*	.10	.22	.39
3 (b) NATURAL Non-clumsy				-	.14	.44	.04	.50*	.15
4 (a) COORD Clumsy					-	.47	.26	.21	.08
4 (b) COORD Non-clumsy						-	.01	.18	-.05
5 (a) FINE Clumsy							-	.49*	-.11
5 (b) FINE Non-clumsy								-	.25
									-

\*  $p < .05$ ; \*\*  $p < .01$